

EMPOWERING LIFESPAN RESPITE CARE PROGRAM LEADERSHIP
in Implementation of the
NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

*Final Report of the Lifespan Respite Learning Collaborative
on National Strategy Implementation*





ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network includes the National Respite Locator that helps caregivers and professionals locate respite services in their community; the National Respite Coalition, which is the policy division of ARCH; and the Lifespan Respite Technical Assistance and Resource Center, funded by the Administration for Community Living in the U.S. Department of Health and Human Services.

ACKNOWLEDGMENTS

ARCH wishes to thank Cheryl Dinnell, ARCH Consultant, who expertly facilitated the Lifespan Respite Grantee and Partner Learning Collaborative on Implementing the National Strategy to Support Family Caregivers from October 2023 through September 2024 and was the primary author of this report. ARCH is also grateful to the Lifespan Respite grantees and partners for their meaningful participation in and generous contributions to the Learning Collaborative, and to the national experts who lent their expertise to the process. ARCH also wishes to acknowledge Megan Kluth, who helped organize and facilitate the Learning Collaborative during its first six months.

Empowering Lifespan Respite Care Program Leadership in Implementation of the National Strategy to Support Family Caregivers

National Strategy to Support Family Caregivers Learning Collaborative (LC) prepares leaders in the Lifespan Respite Network to take charge on key National Strategy goals.

Leadership is behavior — an observable set of skills and abilities.

Contents

Executive Summary	3
<i>Lessons Learned</i>	3
<i>Recommendations</i>	4
Lifespan Respite Care Program	5
Lifespan Respite Aligns with the National Strategy	5
Lifespan Respite Role in National Strategy Implementation.....	7
National Strategy Learning Collaborative: Preparing Lifespan Respite for Leadership.....	10
<i>Launch of the National Strategy Learning Collaborative</i>	12
<i>Securing Resources</i>	12
<i>Strengthening the Direct Care Workforce</i>	13
<i>White House Action to Advance the National Strategy</i>	14
<i>Laying the Foundation of Leadership</i>	14
<i>Principles for Leadership</i>	15
<i>Lifespan Respite Leaders Mentor Their Peers</i>	18
<i>Rich Dialogue in Finding Solutions</i>	22
Successes, Challenges, and Lessons Learned in National Strategy Implementation	23
Recommendations & Conclusions	29

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

Executive Summary

Lifespan Respite grantees and partners have been at the forefront of efforts at the state level to serve family caregivers. Many of their activities closely align with the [2022 National Strategy to Support Family Caregivers](#) (hereafter referred to as the “National Strategy”), which includes a broad range of goals and objectives that national, state, and local entities have been charged to explore and implement. Because of the infrastructure and partnerships that they have already built, Lifespan Respite grantees and their partners are poised to assume leadership at the state level on these national goals, as they relate to respite, namely increasing awareness of family caregivers, advancing partnerships and engagement with family caregivers, strengthening caregiver services and supports, ensuring financial and workplace security for family caregivers, and expanding data, research, and evidence-based practices to support family caregivers. With ARCH support through a learning collaborative that focused on building and strengthening leadership skills, the Lifespan Respite Network grantees and partners have demonstrated their capacity and commitment to advancing the National Strategy framework, as reported in a [matrix of activities](#) gathered from participating states.

Lessons Learned

- **Raising awareness about, and embedding National Strategy goals in Lifespan Respite Care Program activities, led to successful implementation of National Strategy objectives and recommended actions.** Many of the Lifespan Respite grantees and partners have dedicated time to aligning their current grant activities with National Strategy goals, or have embedded national strategy goals and objectives into their state planning processes, task force work, or grant applications and work plans for future activities. Others have used the weight of the National Strategy to bolster and lend evidence to advancing new state policies and programs that support family caregivers.
- **Sustained funding through synergistic partnerships is crucial for success in National Strategy implementation.** Lifespan Respite grant funds provide a solid foundation on which to build, but are insufficient alone to fully implement National Strategy actions to improve respite service delivery. State partners need to demonstrate buy-in, lend additional support toward common goals, and dedicate funding towards shared efforts. National Strategy implementation requires Lifespan Respite programs to successfully leverage their funding and their partnerships, and to think creatively.
- **Improved communication would enhance key partnerships and identify new ones.** State respite coalition and other partners emphasized the importance of enhanced communication with the state agency regarding review of National Strategy goals and

how to implement them. Strategic and effective communication can also help identify partners who need additional support or identify new untapped partners and resources.

- **Lifespan Respite experience is a model for state implementation of National Strategy goals.** Where Lifespan Respite grantees are taking the lead, they are having a meaningful impact on raising awareness about the national strategy. Lifespan Respite grantees have experience in engaging a range of groups of family caregivers and providers, building coalitions, and sustaining important collaborations, especially with partners who are not normally engaged in caregiving, that others can learn from and emulate.

Recommendations

- ***Streamline access to respite services by encouraging cross-agency collaboration and eliminating local- and state-level silos.***
- ***Scale up self-directed respite models. [See [ARCH Self-Directed Respite Guide](#)]***
- ***Develop State Respite Plans to align with National Strategy goals, and engage new leaders, partners, and visionaries in the state respite planning process.***
- ***Build and strengthen collaboration between Lifespan Respite grantees and State Medicaid agencies.***
- ***Prioritize, and provide resources for, the development, improvement, and expansion of recruitment, training and retention of respite care workers.***
- ***Build or expand state respite care provider registries that link trained workers to families searching for providers.***
- ***Identify and implement meaningful strategies to engage family caregivers from historically marginalized, underserved or under-resourced groups to share respite information and services.***
- ***Ensure that when family caregivers receive financial assistance for providing care through Medicaid or other programs, they don't lose respite care eligibility and backup support.***

Lifespan Respite Care Program

The Lifespan Respite Care Program, enacted under Title XXIX of the Public Health Service Act (42 U.S.C. 201) in 2006, and reauthorized in 2020 through enactment of the Lifespan Respite Care Reauthorization Act of 2020, was created to support the more than 50 million family caregivers who provide continuous care to their spouses, children, grand-children, friends, and other family members with a disability or health condition. Lifespan Respite is defined in the Lifespan Respite Care Act as "a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs."

Family caregivers – who provide the overwhelming majority of long-term services and supports in the United States – often lack resources to maintain their own health, wellbeing, and financial security while providing crucial support for others. Lifespan Respite Program grantees work with key partners in their state to address the universal need of family caregivers to regularly receive temporary relief from the arduous demands of providing on-going care over extended periods of time to friends and family members.

Since the Lifespan Respite Care program was first funded in 2009, the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services has funded thirty-eight states and the District of Columbia to establish or enhance Statewide Lifespan Respite coordinated systems, provide planned and emergency respite care, recruit and train respite workers and volunteers, and connect family caregivers to respite information and services.

Lifespan Respite Aligns with the National Strategy

The [2022 National Strategy to Support Family Caregivers](#) (hereafter referred to as the “National Strategy”) was created to support family caregivers caring for persons of any age or condition and developed jointly by the advisory councils established by the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) and the [Supporting Grandparents Raising Grandchildren \(SGRG\) Act](#), with extensive input from family caregivers, the people they support, and other key players, who explored and documented the challenges faced by family caregivers, kin and grandparent caregivers, respectively.

“The Lifespan Respite Care grantees and partners...are at the forefront of designing and delivering so many innovative, person- and family-centered services ...(that) can be a model for others who support and serve family caregivers in your state.”

Launch of the National Strategy Learning Collaborative, February 2023

The National Strategy includes an abundance of important and relevant information and guidance to support caregivers, and proposed hundreds of actions that states, communities and others could take to improve the lives of family caregivers. Given the breadth and complexity of the National Strategy, in the 2023 report, [*The Role of Respite in The National Strategy to Support Family Caregivers*](#), ARCH identified the unique role that Lifespan Respite grantees and their partners could play in streamlining implementation of the National Strategy's recommended actions, especially those focused on respite care, and embedded in the following goals:

Goal 1: Increase awareness of and outreach to family caregivers

Goal 2: Advance partnerships and engagement with family caregivers

Goal 3: Strengthen services and supports for family caregivers.

Goal 4: Ensure financial and workplace security for family caregivers.

Goal 5: Expand data, research, and evidence-based practices to support family caregivers.

Since 2009, respite grantees and coalitions have built a long history of successful collaborations with businesses, higher education, health care systems, child welfare, Tribal nations, among

“Many feel they are addressing the National Strategy recommendations and goals through the robust work they have been doing, in some cases for over a decade.” –

Amy Harris, Colorado

others, but most importantly, with family caregivers and service providers – the people closest to the implementation of these National Strategy’s goals and recommended actions and most affected by them. Through local knowledge of the unique needs and resources in their states, regions and communities, Lifespan Respite grantees and their partners are uniquely situated to advance the National Strategy’s recommended respite actions.

Existing products and activities that Lifespan Respite Program grantees engaged in were matched to these goals, providing a baseline for alignment with the National Strategy. This [matrix of activities](#) was updated in May 2024 to reflect the continued efforts of grantees to implement recommended actions in the National Strategy and help inform next steps for the new RAISE Family Caregiving Advisory Council.

Recognizing the alignment of the Lifespan Respite Care Program with successful implementation of the National Strategy, this matrix was highlighted in a publication from the National Academy for State Health Policy (NASHP), [*National Strategy to Support Family Caregivers Progress and Impact Report 2024, State and Community Actions*](#), and also used to inform the development of [*Respite Care: State Policy Resource Guide*](#) developed by NASHP in collaboration with ARCH with support from the John A. Hartford Foundation.

As part of its mission to advance the National Strategy, NASHP held a Respite Summit in February 2024 in collaboration with ARCH that brought together Federal Medicaid, Aging, Disability and Public Health agencies; State Medicaid, Aging and Disability agencies, and Lifespan Respite grantees and partners, to discuss ways to enhance respite services and policies at the state level. The summit was summarized in the document [State Innovations to Advance Respite Care: Policy Strategies Shared at the State-Federal Respite Summit](#).

Lifespan Respite Role in National Strategy Implementation

The Lifespan Respite Care Program capitalizes and improves upon existing assets in grantee states and localities. Through local knowledge of the unique needs and resources in their 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 family members and friends over extended periods of time. Identifying and then serving these family caregivers has been a critical endeavor in these programs. Respite priorities were also recognized and included in the goals and objectives of the National Strategy as directed by the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#).

To clarify the important role that respite could, and should, play in the National Strategy, ARCH produced a [policy to practice brief](#) that gathered explicit examples and unique opportunities to implement the identified respite actions through existing Lifespan Respite programs, services, and systems. These examples and opportunities reside in four areas: Planning and Decision-Making; Information and Access; Person- and Family-Centered Services; and Workforce Development. As outlined below, there is no question that the expertise, leadership, and implementation experience available through Lifespan Respite Network grantees and partners would lend significant support towards realizing the promise of the National Strategy.

- *Planning and Decision-Making*

State Respite Coalitions have a history of, and expertise in, assessing community needs and resources, planning and participating in deliberating and decision-making bodies, and aligning services and funding resources. Educating and involving partners is prerequisite to coordinated and collaborative planning and decision-making that can streamline access to respite for family caregivers.

Even for those states without a functioning Lifespan Respite grant or State Respite Coalition, using the lifespan respite systems building model, and adopting an inclusive, systematic approach, could provide the foundation needed for implementing respite actions recommended in the National Strategy.

Lifespan Respite grantees in Nevada and New York provide examples of how states have embedded grant activities in, or collaborated with, their No Wrong Door Systems to build seamless access to respite services.ⁱ

A number of state Lifespan Respite grantees in collaboration with their State Respite Coalitions, family caregivers, and other key partners undertake deliberative planning processes to develop state plans to support family caregivers, and guide implementation of sustainable Lifespan respite systems.ⁱⁱ South Carolina has taken it a step further by solidifying coordination and partnerships through state and regional committees and integrating Lifespan Respite with other state Long-term Services and Support (LTSS) systems.ⁱⁱⁱ

- *Information and Access*

The National Strategy describes a number of conditions that compromise family caregivers' access to services — lack of flexibility or understanding of caregiving demands in the workplace; lack of understanding of available services and supports and how to find and afford them; lack of available persons and programs that are culturally or linguistically competent to serve all families; and lack of available human supports to offer guidance and follow-up as family caregivers navigate multiple systems or experience changes in their caregiving circumstances. Extensive expertise in meeting these challenges lies within the Lifespan Respite Network as respite systems and programs across the nation have grappled with all these barriers to access and have diligently worked to address them.

For working caregivers, current and former Lifespan Respite grantees and their partners in Nebraska, New York, and Wisconsin, have been educating employers about the needs of their employed caregivers through anonymous workplace surveys.^{iv} New York partnered with their state Department of Labor to engage employers by disseminating information about how to support working caregivers. Other state grantees educate employers about respite and caregiver support through Employee Assistance Programs, lunch and learn meetings, and printed materials.^v

Lifespan Respite Washington and the Washington Lifespan Respite grantee have built important partnerships with Tribal nations and engaged in deliberative strategies to ensure geographic reach and diversity in service delivery.^{vi} The Tennessee Caregiver Coalition embeds proven person-to-person approaches to engage family caregivers from communities across the state.^{vii} The Idaho Caregiver Alliance runs the Family Caregiver Navigator, that includes Spanish-speaking navigators, to help family caregivers find respite and other supports.^{viii}

- *Person- and Family-Centered Services*

Person- and family-centered services are a key focus of the National Strategy to ensure that services and supports are varied, flexible, and match caregiver and care recipient needs as circumstances change over time. Similarly, respite services are intentionally designed to be flexible and individualized, and the Lifespan Respite Network provides numerous examples of best practices in serving family caregivers.

Respite services tend to be individually matched and tailored in ways that support caregivers and families in important contexts and in culturally informed ways. Respite programs, capitalizing on close relationships with caregivers and families formed over time, increasingly include individualized emergency planning and long-term planning services to caregivers and families.

Twenty-two of the Lifespan Respite grantees provide respite vouchers (also known as stipends, grants or reimbursements) to help family caregivers pay for respite services through self-directed programs.^{ix} Self-direction in respite provides the care recipient and their family/friend caregiver control of who provides services and how that is achieved. Choice and control help to ensure that services are person and family-centered and result in satisfaction with services received.

The Respite Care Association of Wisconsin provides funding to Tribal Nations to manage their own self-directed respite program. The objective is to increase the likelihood of Native caregivers accessing respite care when they can self-direct and select the respite care provider of their choice.^x

- *Workforce Development*

The National Strategy acknowledges and emphasizes the detrimental effects of longstanding shortages in the professional direct care workforce. National and state attention to this worker crisis provides new opportunities to expand and train the direct care workforce — a goal Lifespan Respite programs and systems have long endeavored to address. Like most long-term services and supports, respite programs and services have struggled to recruit, train, support, and retain direct service providers. The Lifespan Respite Network has been at the forefront of developing and evaluating respite provider recruitment strategies and training - efforts that have important implications for how other programs and institutions serving caregivers and their families grow their workforce.

In partnership, ARCH, NASHP, and the Respite Care Association of Wisconsin (RCAW) developed the [National Respite Care Provider Training](#)^{xi} and a recruitment strategy that was field tested in 10 state pilot sites, most of which were overseen by Lifespan Respite grantees or partners. An evaluation consultant monitored the effectiveness and reach of the training and marketing strategies.

National Strategy Learning Collaborative: Preparing Lifespan Respite for Leadership

With the strength of the Lifespan Respite Network established and the alignment with the National Strategy so evident, efforts were undertaken to prepare the Lifespan Respite grantees and their partners to enhance their performance in implementing National Strategy goals and objectives. In February 2023, an ARCH Learning Collaborative on Implementing the National Strategy was launched to provide information to Lifespan Respite grantees and partners about the National Strategy, guidance from national experts on best practices and funding approaches for Strategy implementation, and opportunities for peer-to-peer learning.

“These Learning Collaboratives are so important and the information and tools shared will help the coalitions and Lifespan grantees really up their game.”

*Kathy Mayfield-Smith
South Carolina Respite Coalition*

Eventually, as the Collaborative evolved, focused technical assistance and training on leadership skill development for Collaborative members were envisioned as the tools needed to move forward on National Strategy implementation.

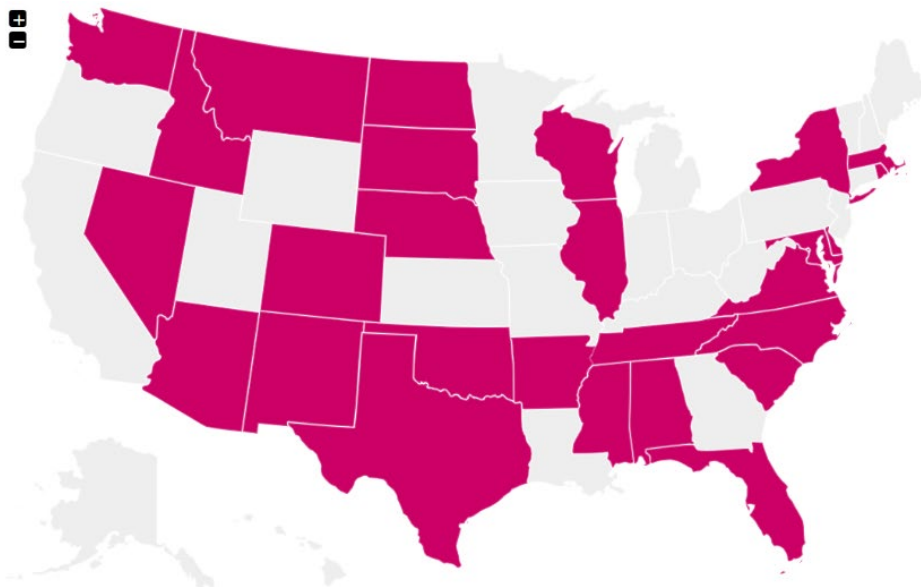
The first five ARCH Learning Collaborative (LC) sessions focused on understanding the five goals and objectives included in the National Strategy, and hearing from experts about broad strategies (e.g., state policy actions, direct care workforce strategies) that can be used to advance the National Strategy. It was understood that each individual participant or representative in the learning collaborative would likely address different recommended actions under one or more of the Strategy’s goals, in their work related to respite care services and supports.

The new learning collaborative provided dedicated time to explore how these respite actions currently are, or could be, embedded into current Lifespan Respite grant work plans, as well as support new ways to increase access to and awareness of respite services in the states, and identify and establish new partnerships.

Meetings of the collaborative were held frequently between February 2023 and September 2024 to provide participants with many opportunities to connect with others interested in

National Strategy implementation. Almost three-quarters of the 124 participants who participated in one or more Learning Collaborative meetings between Feb 2023 and Sept 2024 identified as the state Lifespan Respite grantee, with 37% of participants representing their state respite or caregiving coalition. Participants in the learning collaborative came from 27 states and the District of Columbia, representing 69% of current and former Lifespan Respite Grantees. ¹

States Represented in the Learning Collaborative



Learning Collaborative participants in the November 2023 meeting were asked where they planned to focus efforts to implement the National Strategy at the state level. Two areas rose to the top: Awareness & Outreach (33%) and Strengthening Services and Supports (33%). Another twenty-nine percent responded that their effort would go towards building partnerships and engaging family caregivers in this work.²

By February 2024, LC participants were working at various stages of implementing their National Strategy goal/priority. Sixty-one percent said they were engaging in motivational and educational interventions to prepare others for change related to the National Strategy; 29% were engaged in enabling and skill building interventions to enact new practices around National Strategy goals and objectives; and 11% were already reinforcing the structural and financing interventions needed to sustain the changes made.³

¹ LC Attendance Records and National Strategy Feedback Survey, August 2024.

² LC Polling Question Results, November 2023.

³ LC Polling Question Results, February 2024.

Launch of the National Strategy Learning Collaborative

When ARCH launched the Lifespan Respite Grantee and Partner Learning Collaborative in February 2023, most of the participants generally had some awareness about the National Strategy, but 42% were not familiar with it at all.⁴

The [first session](#) focused on providing sufficient information and background on the National Strategy to ensure that all participants were well informed. **Wendy Fox Grage**, Senior Policy Director with the National Academy for State Health Policy (NASHP), who oversees the work of [The RAISE Act Family Caregiver Implementation and Technical Assistance Center](#), provided a comprehensive overview of the Strategy, its goals, and intended reach.

She also highlighted steps Lifespan Respite Grantees and Partners could take to advance the respite actions within it. She highlighted best practices in state Lifespan Respite programs that align with the National Strategy and could be replicated in other states, such as resource

directories, respite training curriculum, mini-grants for faith-based and volunteer respite initiatives, and educational tools for family caregiver identification and assessment.

“This whole collaborative ... can pull out those respite actions and highlight what those are ... so that we can move the needle forward [on the National Strategy].”

Wendy Fox-Grage, NASHP

It was identified early on that two paramount issues need to be addressed for successful implementation of the National Strategy: 1) Securing additional

resources for scaling up promising respite and related actions; and 2) Addressing the direct care workforce crisis that is identified in the National Strategy as a critical cross-cutting need.

Securing Resources

To address these needs, the learning collaborative launch was followed by several sessions focused on approaches to state policymaking and diversified funding to help Lifespan Respite programs scale up their implementation of the National Strategy. **Siena Ruggeri**, Policy Analyst, Center for Consumer Engagement in Health Innovation, Community Catalyst, described the impetus and purpose for their [Changing the Care Conversation Project](#), and presented highlights from their work with 10 state-based family caregiving coalitions in advancing state and federal policy solutions that strengthen supports for family caregivers. After seeing a need for specific leadership training and capacity-building to enable family caregivers to take an active role in advocating for improved caregiver policies, efforts focused on creating a group of caregiver

⁴ National Strategy LC Feedback Survey, August 2024.

leaders who could then equip and strengthen others in their local communities to engage in advocacy.

Also, in this session on [Approaches to State Policymaking and Diversified Funding](#), three Lifespan Respite Grant partners from Alabama, New York, and Wisconsin shared their unique approaches to affecting state policy change and diversifying respite funding streams in their states. They discussed how to build on their partnerships for “value-added” mutual benefit rather than competition. They also shared how to build relationships with legislators who understand caregiving from personal experiences and would champion legislation and local, state, and federal funding of respite services and supports.

Wisconsin is one of three states that has enacted legislation authorizing a State Lifespan Respite Care Program, and the state funding provides match for other federal and public/private grants. After years of demonstrated success in grant administration, invitations to apply for specific grants have been extended to the Respite Care Association of Wisconsin, which administers the State Lifespan Respite Care Program. Opportunities to diversify funding from national organizations, higher education, foundations, and state leadership have strengthened the sustainability of the program. Being active in state and national coalitions, alliances, taskforces, and other curated relationships have built important connections for further success.

Similarly, Alabama Lifespan Respite started with funding from a regional nonprofit to establish a respite program in a limited number of counties. The successful impact of that program led to grassroots efforts to form a taskforce that identified gaps in services and helped share resources statewide for six years. This effort resulted in a governor-appointed coalition and state legislation that recognized Alabama Lifespan Respite as the lead entity to coordinate respite and offer caregiver services and support in the state. Partnerships with all of the different agency representatives on the coalition has created connections to caregivers caring for persons of all ages and conditions, diversified their funding streams, and sustained growth in the program.

Sustainability takes time and effort. New York has also diversified funding through federal, state and foundation grants. Currently, the process for developing a Master Plan on Aging has provided opportunities for Lifespan Respite leaders in New York to engage with other key agencies and organizations to advance the National Strategy, to help advocate for legislative action on respite, and forge new relationships. Other state leaders in the Lifespan Respite Network have been invaluable to the New York team in helping them grow and develop a voice at the state capital.

Strengthening the Direct Care Workforce

Learning Collaborative sessions also focused on [state actions to strengthen the direct care workforce](#). **Kezia Scales**, Vice President of Research & Evaluation, with PHI, Quality Care through Quality Jobs, provided expert guidance on best state practices on strengthening the

direct care workforce to help guide Lifespan Respite grantees and partners in their work in growing the respite care workforce. Several high-level, Medicaid-centric examples were shared on increasing worker compensation and benefits, training standards and career pathways, data collection to determine where to focus intervention efforts, and shifting the public perception and narrative around caregiving. A discussion followed on state-specific barriers to effectively deal with the workforce crisis for respite providers, and some of the strategies states were using to overcome these barriers. Participants also shared their thoughts about which of the best practices presented might be most realistic to implement in their respective states.

White House Action to Advance the National Strategy

In April 2023, the White House released the very timely [Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers](#). During the [June 2023 LC meeting](#), the LC participants reviewed the Executive Order and shared how select actions might impact Lifespan Respite efforts in their respective states. To inform the discussion, ARCH summarized and shared the respite actions in the White House Executive Order in the document, [Highlights of Important Actions for Respite and Support for Family Caregivers - White House Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers](#).

Laying the Foundation of Leadership

By October 2023, since learning about the National Strategy for Support of Caregivers, 83% of LC participants reported having completed a review of the recommendations in the National Strategy, 50% had selected recommendations for new or continued effort, and 58% had started conversations with other state leaders about implementing recommendations. Seventeen percent of participants polled had already formulated plans and agreements with others on working together on National Strategy goals and objectives.⁵

“Leaders usually come forward naturally, but leadership need not always be top down. Those not in assigned leadership positions can ask questions, solicit guidance, tease out details of how the plan would come together, identify people’s strengths and interests, and recognize everyone’s efforts.”

Learning Collaborative Group Discussion on

To best assist them, a shift to technical assistance and training on leadership skill development was implemented to move forward on National Strategy implementation. In October 2023, the National Strategy LC redirected its purpose to provide participants with stronger leadership skills to further state efforts to implement respite and other actions in the

⁵ LC Polling Question Results, October 2023.

National Strategy. A new [framework](#) for the Learning Collaborative was developed to guide the structure and content for the group going forward.

In each Learning Collaborative meeting, the Learning Collaborative facilitator presented a motivational and educational lesson on one of the leadership principles described in the framework. Leaders from the Lifespan Respite Network accepted opportunities to mentor their peers and colleagues through formal presentations. In these presentations, they demonstrated the leadership principles in practice and how specific skills were utilized to implement respite workplan actions or address related National Strategy goals and objectives. Discussion groups were held to discuss the leadership principle presented. Using a prepared discussion guide, LC participants shared how the principle affected their personal or work capabilities to lead implementation of the National Strategy.

Principles for Leadership

The LC facilitator addressed the following well-established leadership principles as best practices to becoming a better leader.

- *Model the Way: Foundation of Leadership*

Leadership ability and management skills are often used interchangeably, but there are key differences. Leadership skills focus on inspiring and motivating others to achieve a common goal, not just managing tasks. This means setting a clear vision, communicating that vision, and mobilizing people to work towards it.

- *Inspire a Shared Vision*

Communicating vision is the ability to paint a vivid and inspirational picture of a future state that rallies individual and collective support to act. Before leaders approach potential partners, they need to know how to develop a clear vision of their cause, goals, and how they align with their organizational mission and values.

- *Enable Others to Act: Partnerships*

Leaders need to know how to research the interests, strengths, and challenges of the organizations they want to collaborate with. This will help them identify areas of mutual benefit and avoid potential conflicts. Identifying the right partner is a critical element of successful campaigns promoting the National Strategy and its proposed actions.

“Our ask is what do they want to contribute to this larger framework ... see how they fit into a bigger picture of the National Strategy. Some people may jump in, but others may need shepherding by giving them ideas about how they can contribute.”-

Learning Collaborative Group Discussion on Partnerships

- *Challenge the Process: Overcoming Barriers*

Lifespan Respite organizations will face barriers in translating the National Strategy into action. There are typically four barriers to implementing any effective strategy: (1) vision barrier, (2)

“The question becomes “what can we do with what we have got?” and may require a vision to narrow and strategies to take smaller incremental steps, to get some progress.”

Learning Collaborative Group Discussion on Overcoming Barriers

people barrier, (3) management barrier, and (4) resource barrier. Leaders must learn innovative ways to change, grow and improve to overcome these barriers. Leaders also constantly question how things are done in their organizations. They identify processes that do not work and take action to fix them. The top identified barriers for Lifespan Respite grantees and partners were reported by participants as Resources (42%) and People (29%).⁶

- *Persuasion*

Power and influence are used to get others to act; power is based on positional authority while influence is based on relationships. Persuasion skills allow leaders to change or inspire another person's viewpoint by influencing them through verbal or nonverbal communication.

The persuasive style of public speaking aims to convince, motivate, or persuade an audience to adopt a certain point of view, attitude, or behavior - not just informing them, but also influencing them. Leaders appeal to their audience's emotions, values, and logic, and overcome their objections or doubts - with the use of strong, compelling, and engaging language, and supporting key points with credible evidence, examples, and testimonials.

- *Encourage the Heart: Performance*

Good leaders create a positive work environment, motivate those they work with, and provide clear direction and guidance. This can lead to increased efficiency and productivity. A more engaged and committed workforce is a high-performing one. Trust and rapport are also the foundation of any successful partnership. The ability to cultivate a culture of mutual respect, appreciation, and accountability among partners is central to strong leadership. This can be done by acknowledging their contributions, celebrating their achievements, and providing constructive feedback.

- *Prioritization: Managing Time*

Leaders in Lifespan Respite must balance multiple activities and roles in addition to National Strategy implementation. Fifty percent of participants in this session said that managing

⁶ LC Polling Question Results, February 2024.

constant interruptions was their top time management challenge.⁷ Time management is the process of organizing and planning how to divide a leader's time between different activities, as the coordination of tasks and activities maximize the effectiveness of an individual's efforts. When leaders are good at time management, they feel confident about completing assigned tasks within an allocated timeframe, providing accurate estimates of how much time is needed to complete tasks, and accurately following through on commitments. Essentially, the purpose of time management is to enable people to get more, and better, work done in less time.

- *Taking Steps Forward together: Negotiation*

Negotiation involves two or more people finding an acceptable solution to a shared problem. Successful negotiators control the process and come away with a result they're satisfied with – whether they must make some compromises along the way. For projects to be successful, roles, strategies, targets, and deadlines all need to be agreed on, ideally to everyone's satisfaction. Negotiation is a critical skill for leaders, as it enables them to navigate complex situations, resolve conflicts, and reach mutually beneficial agreements with others.

- *Personal Ecology: Resilience, Discipline, and Self Care*

Leaders recognize that it is more difficult to contribute to the world in a positive and sustainable way without taking care of oneself first and recognizing one's own unique responsibilities and capacities. Resilience is the ability to cope mentally and emotionally with a crisis, and to return to pre-crisis status quickly - to move through and grow from tough times, and keep going, both physically and psychologically.

“When life events cause big disruptions, everyone must step up to share the load, see where things can be simplified, and be very understanding of the load others are carrying.”

Lisa Schneider, Wisconsin

Self-discipline is required to lead a group, to create and maintain concrete growth, and to ultimately have a meaningful impact. Self-discipline is the ability to resist impulses, maintain focus, and see projects through to completion. It is categorized by a leader's persistence and willpower in dedicating their

attention to a task until it is satisfactorily achieved. Leaders who can practice self-discipline are not easily distracted and can maintain focus despite other priorities or requirements for their attention.

Self-care is the practice of taking action to preserve or improve one's own health and taking an active role in protecting one's own well-being and happiness, particularly during periods of

⁷ LC Polling Question Results, June 2024.

stress. Moreover, a leader must be prepared to deal with staff turnover and reducing burnout, by having a succession plan in place.

Lifespan Respite Leaders Mentor Their Peers

While Lifespan Respite Network grantees and partners have always generously shared their strategies for providing respite services and supporting family caregivers, numerous key leaders presented their experiences in leadership topics covered in LC sessions. Some have made significant strides in implementation of priorities that align with the National Strategy. These LC guest presentations proved to be extremely or very helpful to 74% of LC participants responding to a final feedback survey in understanding or informing their work on the National Strategy.⁸

Leadership Principle: Model the Way. **Adrian Rodriguez** and **Sheila Weaver** from the Idaho Caregiver Alliance talked about their process in selecting priorities that reflect recommendations from the National Strategy and how they expanded their services to better reach the Hispanic population in their state. They discussed the steps they took, the products they developed, and shared what they learned from their experiences in outreach to the Hispanic population of caregivers in Idaho – strategies that could benefit others who were trying to do the same elsewhere. It began with a simple conversation about “how could they know of complaints” from Hispanic community when there was not a complaint form in Spanish that they could use. They had to consider how mindful they were in engaging the Hispanic community.

One question to answer was “where do Hispanic families receive their information?” Social media posts were only in English, so another Facebook page was created for Spanish-speakers. Intentionally making a separate site allows them to build and maintain connections with respected people and organizations in the Hispanic community.

Leadership Principle: Inspire a Shared Vision. **Deana Prest** and **Abbey Derepentigny**, from the New York State Office for the Aging (NYSOFA), and **Doris Green** from the New York State Caregiving & Respite Coalition (NYSCRC) discussed their journey in visioning the Lifespan Respite Care system in New York State, and shared how they attracted collaborators and family caregivers to the work by conveying their message and enthusiasm to others. They shared what they learned at various points in the planning process, and the work involved in the development of various initiatives.

Every year, they engage in sustainability planning and enhance their strategic planning logic model to expound their vision of supporting New York’s family caregivers.

⁸ National Strategy LC Feedback Survey (N=19), August 2024.

With core partners from the NYSOFA, NYSCRC, and NY Connects (No Wrong Door), they make sure to consider each program when they do anything related to respite and caregiving – and consider the whole lifespan respite system across the state. Key to their successful collaboration has been meeting regularly, thinking as a team, thinking “Big Picture” when working on grants, pilots or new programs, taking a strengths-based approach to valuing the contributions of each team member and engaging in brainstorming to build and enhance their strategic plan. This collaborative approach is also applied with other partners in the state.

As New York worked to expand caregiver-directed respite through the National Family Caregiver Support Program, a workgroup was formed to examine creating new options for respite – and the expanded use of respite vouchers. The NYSCRC was included in deliberations to learn what the Area Agencies on Aging (AAAs) and caregivers thought would be beneficial. One challenge

“Every single time the NY Office for the Aging is working on a project, no discussion or planning is approached without having the Respite Coalition and other partners in mind.”

Deana Prest, New York

was overcome when NY’s AAAs were given permission from the state to use the Respite Coalition as a fiscal intermediary for the respite voucher program. The expansion of respite vouchers from the pilot program at NYSCRC to AAAs across the state provides an excellent example of how to scale up a successful respite initiative.

Leadership Principle: Enabling Others to Act. Amy Nazaire and Lisa Marschke with the Massachusetts Lifespan Respite Coalition, and Ashley Woodman from the UMass Campus to Community Program, provided a brief overview of the MA Lifespan Respite Project. They shared examples of strategies they used to achieve consensus among various key partners. They also discussed building relationships that have resulted in non-traditional ways of expanding respite opportunities and how they motivated others to join them in the work.

Massachusetts met with respite partners individually to find out how they defined respite. They then brought a large group of providers together to create a cohesive definition that was respectful of all members, the clients served, and the program goals they sought to achieve. The definition agreed upon gained team ownership of the results, with additional benefits of team building, and gave steps each state agency could take to further define terms, such as caregiver, special needs, exceptional, support, etc.

In the UMass Campus to Community Program, leaders of two different organizations realized that one had two hundred students who needed 120 hours of experience serving the

developmental disability population, and another was struggling to help family caregivers find respite providers – and families did not want just anyone! From this mutual need, a service-learning course was developed for multidisciplinary students across the campus with a 3-hour service requirement. The course organizers learned about the MA Lifespan Respite Coalition and a new partnership was forged. With new funding from the Lifespan Respite Care grant, the program now offers stipends to students to work as respite providers while reaching career goals. Families can expect a certain level of support from the students because they are now employed as respite workers.

Two other collaborations have resulted from these initial partnerships. A new nursing training in the eastern part of the state is underway for children with complex medical needs and, because of overlapping interests, respite training and materials from the Campus to Community program were shared. Now both multidisciplinary students and nursing students are serving as respite providers. Multidisciplinary students will get training experience with more complex medical needs, allowing them to get future jobs as respite care providers, personal care assistant (PCA) or complex care assistants.

Leadership Principle: Challenge the Process. **Lita Nelson** from the Arizona Department of Economic Security, Division on Aging and Adult Services, and **Dr. Nelly Clotter-Woods** and **Charlotte Holiday** from the Arizona Caregiver Coalition, provided examples of the strategies they have used to overcome barriers and extend their outreach, awareness, and support activities through their Lifespan Respite grant. They worked together to develop a plan to address the legislative mandate they were given to create a Caregiver Resource line.

A state statute in 2007 mirrored the Lifespan Respite Care Act and would have provided funding and staff to administer and develop a State-funded Lifespan Respite Care Program, but without a champion, no appropriation was made. It was determined that coordination among agencies, funding, and key partners was needed to promote public awareness of respite, help caregivers self-identify, and to address service gaps, waitlists, and staff shortages. They overcame these barriers to implement the Caregiver Resource Line through their No Wrong Door system. The Resource Line has been successful in connecting caregivers with respite services, providers, and payment resources, while also identifying gaps in services. This new level of awareness led to the Governor’s support of the state’s expansion of paid family leave benefits to family caregivers.

Leadership Principle: Performance Presenters **Amy Harris**, Colorado Department of Human Services, State Unit on Aging, and **Megan Bettinger**, Colorado Respite Coalition, shared how they inherited the Colorado Respite Coalition after a global pandemic and significant staff changes and were left to rebuild their program. They led with their hearts, were honest and authentic with each other, formed a close partnership (that led to other close relationships that

would prove crucial to their success), leveraged their lack of institutional knowledge for a fresh take on their programs, and reached out for help. As a result, the Colorado Respite Coalition has been transformed into a flexible, tailored program that helps more people with more resources.

While they inherited an ambitious workplan, they utilized strategic planning meetings to comb through the plan, identify what could and could not be accomplished, and determine what was most important. There are now several programs and services working seamlessly in Colorado.

Leadership Principle: Time Management **Lisa Schneider**, Executive Director, Respite Care Association of Wisconsin, shared her perspectives on time management from her experiences as a leader in Lifespan Respite work, her personal realities as a caregiver, and what she coaches others to do. As a family caregiver with a full-time job, Lisa recognizes that she has many roles that she may have to step into at any given moment. If something goes wrong, she is usually the one who must fix it. As the HR manager, the IT guru, the Administrator, or Executive Director, she's the overall problem-solver who must be prepared for the unexpected – especially when it comes to her family.

The tools Lisa uses include Microsoft Outlook where she can schedule meetings, projects, deadlines, and reminders. She also uses a tool called [Trello](#) where she and her staff manage projects and collaborate with team members. She blocks out times for project work or times held open while waiting for Doodle Poll results, shares her calendar with staff so her availability can be seen, flags emails for follow up, and plugs in family items like doctors' appointments. She color-codes them to avoid double-booking those times with a work commitment.

Leadership Principle: Negotiation Presenter **Kathy Mayfield-Smith**, Associate Director, Institute of Families in Society, University of South Carolina, spoke on the topic *Negotiation: Finding Acceptable Solutions to Shared Challenges*. Kathy is a caregiver, the cofounder of the South Carolina Respite Coalition, and has been involved in the Lifespan Respite movement for many years. She shared some insights and strategies for effective negotiation from her lifetime of experiences, where she has negotiated in a variety of situations and with different partners and personalities.

As leaders of non-profits or as Lifespan grantees, negotiating with funding sources, state agency personnel, providers, community partners, legislators, donors and maybe even family caregivers may be required. Each of the different roles Kathy has held in her life provided her with a different perspective at the negotiation table, and shaped an understanding of how various roles may affect a negotiation. Kathy encouraged participants to recognize and use all their experiences to inform the strategies used for negotiation.

Rich Dialogue in Finding Solutions

Small discussion groups in each LC session were designed to provide a platform for sharing ideas, considering strategies, and finding out how state grantees and their partners persuaded others to join them in making forward movements on the National Strategy goals and priorities

“Because many of those in our audience are in the service field, persuading them to help is not the issue – they want to help. Persuasion comes in taking a direction forward and finding or fitting participants and organizations into the puzzle of the overall National Strategy plan.”

Learning Collaborative Group Discussion on Persuasion, March 2024

they adopted. Sixty-three percent of LC participants said breakout room discussions were extremely or very helpful in understanding or informing their work on the National Strategy.⁹

Discussion questions covered a range of topics and often were drawn from the leadership skill presentations. In randomly assigned breakout groups, participants explored with their peers their understanding of specific challenges and barriers in implementing the National Strategy; found organizational

and personal strengths to build on; learned about opportunities to engage others and build new partnerships, and identified network resources, ideas, and tools, as they answered questions such as these:

- *Are you a champion for implementation on any National Strategy recommendation in your state?*
- *Do you have a vision statement for your efforts aligned with the National Strategy?*
- *How are state grantees and their partners dealing with perceived barriers to forward movement on the National Strategy goals and priorities they have adopted?*
- *How have the values of family caregivers and organizations that serve them helped inform the process?*
- *What are your thoughts about how well prepared and willing the Lifespan Respite Network is to lead in states on National Strategy implementation?*
- *What, if anything, will now be needed to sustain our leadership efforts in the National Strategy?*

State representatives discussed how their Lifespan Respite priorities might better align with the National Strategy, how many of their activities do align, and how having a National Strategy strengthens their positions and supports their efforts. However, National Strategy goals and recommendations for family caregivers have many competing state priorities, such as crime,

⁹ National Strategy LC Feedback Survey (N=19), August 2024.

homelessness, drugs, mass shootings, and other priorities that make it a struggle to get media attention and elevate the needs of caregivers. Even with a good strategic plan for implementation, legislators and state administrators do not engage in moving caregiving issues and concerns forward.

Group discussion led to sharing and considering alternative approaches, such as organizing planning groups focused on a specific target population, rather than bringing a group together around general priorities (such as outreach & awareness, employment, training & education, or expanding services).

Participants discussed engagement strategies to attract new members to their coalitions. They discussed potential partners not yet involved, such as state departments of education, labor, workforce development, and disability councils, among others. Some states shared successful strategies in working with Area Agencies on Aging (AAAs) to review National Strategy goals and steps for implementation.

With a variety of Lifespan Respite peers in the small breakout groups, participants considered a multitude of topics and strategies, including ways to address the needs of underserved populations in their work; ways to keep informed about other efforts in the state to avoid duplication; how to engage family caregivers in coalition activities; and how to participate in legislative activities. Interest was expressed in best practices for sharing data to identify and illustrate service gaps, especially for traditionally underserved populations and counties.

Successes, Challenges, and Lessons Learned in National Strategy Implementation

After attending the National Strategy Learning Collaborative, ARCH conducted a survey of all participants. Although only 19 participants responded to the survey, 68% reported a significantly improved understanding of the content and purpose of the National Strategy, and indicated that the learning collaborative sessions were a very valuable use of their time. Seventy-eight percent reported that they personally gained skills they could use in their work.¹⁰ Many leaders, now aware of the National Strategy, are keeping it in mind as they look at expanding and/or enhancing services.

The Learning Collaborative focused on helping Lifespan Respite grantees and state respite coalitions assume leadership roles in their respective states to facilitate implementation of the respite recommendations in the National Strategy. The LC provided opportunities for peer-to-peer learning and support; training and technical assistance from ARCH; dedicated time to

¹⁰ National Strategy LC Feedback Survey, August 2024.

explore how these respite actions currently are, or could be, embedded into current Lifespan Respite grant work plans. They gained support for identifying new ways to increase access to and awareness of respite services and learned effective strategies to identify and establish new partnerships. Additionally, the updated matrix summarizing Lifespan Respite grantee activities that align with National Strategy goals and objective, updated by the participants, will be used to help inform next steps for the RAISE Family Caregiving Advisory Council in revising and updating the National Strategy.

For many state Lifespan Respite grantees, strategically aligning grant activities with the National Strategy has become part of an internal review before reaching out to other interested organizations and community partners. Early on in the LC, 17% of participants polled had already formulated plans and agreements with others on working together on National Strategy goals and objectives.

While National Strategy implementation moves Lifespan Respite programs to work outside of their usual parameters, leaders are emerging from the network with confidence in their skills and ability to set realistic goals and expectations. Some things may be outside of their control, but they are becoming master communicators and advocates, ready for the challenges they may face.

They also were assured that they are not alone; the Lifespan Respite Network inspires their success. Lifespan Respite grantees willingly share what they know and learn what they can about how others succeed, and celebrate each other's wins, big and small. After participating in this learning collaborative, participants said they were feeling a great deal (26%) or a lot (26%) more confident about implementing National Strategy objectives.¹¹

Leadership on behalf of the National Strategy is always evolving. New leaders may feel prepared to step up but are hesitant to do so if there are aspects of their state system that they are not familiar with. Established state leaders echo a similar discomfort that they need to be more familiar with the National Strategy that is broader than they expected. These leaders pledged to review learning collaborative recordings to prepare for assuming leadership roles in their states. ARCH also provides a repository of information and tools to help Lifespan Respite grantees as they strive to align with and implement National Strategy goals and objectives.

- *Embedding National Strategy Goals in Lifespan Respite Care Programs and Planning Efforts Leads to Successful Implementation*

As discussed previously, many members of the Lifespan Respite network have demonstrated leadership in implementing the National Strategy by first aligning their grant activities with

¹¹ National Strategy LC Feedback Survey, August 2024.

National Strategy goals. This information has enabled them to embed National Strategy goals and objectives into their current workplans, and to plan for embedding them in future activities.

For example, the **Wisconsin** Lifespan Respite grantee and partners examined their Lifespan Respite program activities and established that ninety percent of their program activities fell within the National Strategy's five goals, including those related to data collection. The same process was used with multiple partner organizations to help identify and recognize their own individual alignment with National Strategy goals. This information was compiled into one plan document that demonstrates how partners are working on common goals and where there are gaps. Partners are selecting activities for which they will assume responsibility.

Wisconsin also did a statewide survey, with two online versions (one for professionals and one for caregivers), to rank the National Strategy goals on importance and provide feedback on what activities were needed to implement those goals. The surveys were disseminated to AAAs, children's programs, Aging and Disability Resource Centers (ADRCs) and counties. Hard copies of the survey were distributed in rural communities where internet access may be spotty. Preliminary survey findings show Goal 3 as ranking highest in importance for both professionals and caregivers. The information will help Wisconsin further develop their plan to better support caregivers.

In other examples, **Washington** has embedded National Strategy goals into their Lifespan Respite grant applications to address specific strategies and outcomes, while focusing on revamping their coalition to include more providers and family caregivers. Washington is also working to better serve populations that might be hesitant to participate in respite services. Similarly, as Rhode Island works to align their grant activities with the National Strategy, their proposed state caregiver plan will include strategies for increasing awareness of respite and other caregiver resources among professionals and BIPOC communities, especially in non-English speaking communities.

Oklahoma is using the National Strategy as their guiding document to emphasize where improvements are needed to help support family caregivers, and to provide the impetus and evidence needed to persuade local partners and state leaders to make improvements. With a larger than average senior population among states, the National Strategy has taken on particular relevance. Oklahoma has been able to pass a state tax credit that will provide relief for family caregivers, especially those caring for veterans or individuals with dementia.

Illinois has many existing services and supports for family caregivers that strongly align with the National Strategy. A Lifespan Respite Task Force, meets monthly in committees, and quarterly as a group, and specifically works on Goals 1, 3, and 5 of the National Strategy. As a participant in the [ARCH/NASHP/RCAW respite training pilot program](#), Illinois has been growing their

trained respite workforce and building a provider database, with a broad representation of trained respite workers ready to serve families across the lifespan.

- *Sustained Funding through Synergistic Partnerships is Crucial for Success in National Strategy Implementation*

Even after establishing strong core programs and demonstrating exponential growth in those programs, sustaining National Strategy implementation through a Lifespan Respite program can be difficult when future funding may be limited, if available at all. Securing state funding may depend on identifying legislators with personal caregiving stories who might champion actions that will align with the National Strategy. Such advocacy efforts may be outside permissible activity for Lifespan Respite program administrators and fall to independent state respite coalition partners. Even in states that have designated funding for respite, competing budget priorities must be overcome. It is important that National Strategy goals align with overall state policy priorities.

While Lifespan Respite grants may provide a solid foundation for National Strategy implementation, other state partners need to demonstrate buy-in, lend additional support toward common goals, and even dedicate funding towards shared efforts. National Strategy implementation requires Lifespan Respite grantees and partners to successfully leverage their funding, their partnerships, and to think very creatively.

Rhode Island has been utilizing an ACL Technical Assistance grant which provides 250 hours of service to the state. This grant has been used to bring groups together weekly to share information on data collection around direct care workforce status and its impact on family caregivers. Previously unacquainted partners are working together to see how they can address workforce issues collectively. Such efforts to convene new partners will be critical to National Strategy implementation.

When discussions revolved around a Master Plan for Aging in the state, one Lifespan Respite lead agency was able to make overtures to other state government agencies to see how they might assist in addressing National Strategy recommendations. Some LC participants expressed interest in learning more about the development of Master Plans for Aging in their state and how they might provide input on how family caregiving and respite actions, in line with National strategy goals, could be incorporated. This could be accomplished by adding a question about family caregiving to an agency's intake form; expanding the definition of eligible care recipients; or setting up processes for identifying family caregivers and providing referrals for services and supports.

In **Washington**, the Lifespan Respite grantee has always spearheaded the Coalition but, to work on the National Strategy, it became necessary to expand and reinforce the Coalition by engaging

every agency and program, including Tribal nations, that would have an interest in respite. It involved a massive revamping, with brainstorming about who should be invited across the state and pulling together a new mailing list of contacts. Now, small task-oriented groups have been identified with high expectations for real change as more people outside of the government get involved.

Instead of duplicating other state agency efforts, trying to do it alone, or limiting National Strategy implementation to what they already do well, Lifespan Respite grantees and partners are working on bigger goals together with other agencies and organizations, and leveraging resources to maximize results. This needs to begin when states apply for grant funding, to find synergy with other agency or program objectives and available resources. For example, if there

“Finding and persuading the “one” – a person within a particular organization or community group who can relate to caregiving issues, who is already trusted - can make a huge difference in how successful we are in persuading others to join the effort.”

Cara Ortega, New Mexico

are 5 different grants or programs to fund outreach activities, staff and resources can be coordinated across programs to result in complementary, rather than duplicative or competing efforts.

Some LC participants suggested that a national public awareness campaign for the National Strategy would be very helpful – similar to how a pink ribbon to represent breast cancer is universally known. A national campaign to create recognition about how important unpaid

family caregivers are to health and long-term care systems would generate greater public and private sector support.

- *Improved Communication would Enhance Key Partnerships and Identify New Ones*

Some state respite coalition partners expressed the importance of improving communication with the state lead agency for the Lifespan Respite Care grant. They suggested that the state agencies review state priorities for National Strategy implementation with their partners in order to recognize and understand what partners are already doing. Lead agencies may also need to engage in an open discussion about the support partners may need to successfully take on additional activities to further National Strategy activities.

Even in states where there are frequent meetings between the coalition and the lead agency on Lifespan Respite, learning that existing partners may have more to offer or that there are untapped agencies willing to help, goes unrecognized. For example, there may be untapped allies interested in caregiving. One state leader found that groups representing deaf and hard-

of-hearing/blind and visually impaired individuals wanted to engage in talks about caregiving, but there had not been significant outreach to them.

Other states experienced similar challenges in making people aware of the National Strategy and of any implementation efforts underway. They stated that people unfamiliar with the National Strategy needed to know how they could contribute, even if they did not feel “up to speed.” An onboarding “shortcut” such as a 1-page summary and participant guide – would help new partners and staff understand what the National Strategy was about and how they could help. (Note: [Resources from ACL](#), including a [one page infographic](#) on the Strategy’s 5 goals, and a [social media toolkit](#) with quick caregiving facts, are available to assist with educating team members and the public about the National Strategy.)

Others in the LC interested in building new “outside the box” partnerships around employed caregivers talked about how to better engage employers in providing caregiver support. It was suggested that a business roundtable be convened at the state level that included insurers, employers, managed care organization, medical providers and others to dialogue about private and public sector practices to support family caregivers.

- *Lifespan Respite Experience is a Model for State Implementation of National Strategy Goals*

Lifespan Respite programs have experienced success and overcome challenges in their implementation efforts. Wisconsin notes that the topic of the National Strategy attracts people to meetings to learn more about it. Wisconsin began to train their Dementia Care specialists, family caregiver support coordinators, and other interested parties about the National Strategy goals during National Family Caregiver Month, presenting information on changing demographics, caregiving stress and strain among working caregivers, and how employers can help keep employees healthy and working. Training materials and related information were also made available online about supporting caregivers in the workplace, ensuring their financial stability and showing employers how they can get involved and be supportive of working caregivers.

LC participants in states that have been administering more than one ACL-funded program suggest identifying commonalities among the strategies utilized in these different programs. Conducting a “crosswalk analysis” would enable comparability not only between programs but across different activities. This analysis might help simplify everyone’s approach down to one strategy for all the programs and might be a way to leverage funding and expertise more efficiently to get the work done.

The Rhode Island Office of Healthy Aging has seen results from bringing representatives from agencies in several fields together - to begin to break down siloes. Groups including nursing

schools, social services, agencies that collect and analyze data, local charities, and many others provided an accessible environment for engagement and an opportunity to identify common goals and objectives around the National Strategy that serves everyone at the table, creating real partnerships and encouraging others to join.

Bringing people together had other LC participants thinking about how to connect with faith-based or 55+ active adult communities, because these communities are already actively connecting to caregivers – often without being aware of the caregivers’ role or their needs. Others in the LC advocated bringing back “old-fashioned” community events in rural areas where introductions and grassroots-level stakeholder relationship-building can happen “over a cup of coffee.” These strategies can be applied to many other communities as well.

Finally, Learning Collaborative discussions emphasized that whenever quality services and person- and family-centered practices are desired, training and support will be needed, especially where staff turnover is high. Whenever new caregiver populations are identified, they are likely to be underserved. These challenges require a strategic approach to the National Strategy goals to see where goals and priorities interact or where they overlap. When there is interaction between the interests of any two groups, they are likely to share a commonality with the efforts of others – efforts that can be supported through collaboration.

Recommendations & Conclusions

Over the course of nearly 18 months, participants had the opportunity to learn about and review the National Strategy to Support Family Caregivers; hear from national experts on strategies for scaling up funding and services to support respite and family caregiving or building workforce capacity; participate in leadership skill building; hear from leaders in the Lifespan Respite Network on practical applications of leadership principles, and engage in meaningful discussion on key issues related to program implementation, partnership building, and assuming leadership roles in National Strategy implementation.

The following recommendations emerged from the work of the Learning Collaborative to guide the efforts of the Lifespan Respite Network in leading National Strategy implementation and to improve respite services, and increase respite options and access to care for family caregivers. It is also the intention of the LC to share these recommendations with the RAISE Family Caregiving and the Grandparents Raising Grandchildren Advisory Councils at the Administration for Community Living as they develop the next iteration of the National Strategy to improve respite outcomes for family caregivers.

- Streamline access to respite services by encouraging cross-agency collaboration and eliminating local- and state-level silos (between government agencies, state and local organizations, geographic areas, etc.).*** Several states talked about efforts to reduce silos among partners due to serving different populations, various funding streams, etc. across the lifespan. While some shared progress, this was recognized by many as an ongoing challenge. More effective cross-agency collaboration and communication would help eliminate silos and simplify complex administrative processes, and shorten the time from a caregiver’s application for various respite funding streams to service delivery by revising and streamlining application, eligibility, documentation, matching, and scheduling processes.
- Scale up self-directed respite models.*** Success in implementing self-directed respite programs is well established in the Lifespan Respite Network, but barriers to expanding their reach, including limited resources, remain. Other self-directed models, siloed in Medicaid, Managed Care, Family Caregiver Support, Veteran-directed or State funded programs, may have greater financial resources that impact success. The feasibility of applying lessons learned from Lifespan Respite and other self-directed models to overcome barriers like administrative requirements or documenting eligibility should be evaluated to help states scale up their programs. To get started, ARCH has a [Self-Directed Respite Voucher Guide](#) with Lifespan Respite case studies important tax and financial information; labor department regulations; a self-assessment readiness tool; and additional resources.
- Develop State Respite Plans to align with National Strategy goals. Engage new leaders, partners, and visionaries in the state respite planning process.*** States must leverage key partnerships to implement the National Strategy by growing their State Respite Coalitions. Potential partnerships in the public sector that have not been fully explored might include the Departments of Labor, Education, Workforce Development, Developmental Disability Councils, and Centers for Independent Living. In the private sector, employers, businesses, insurers, and medical and health professionals have important roles in planning sustainable respite systems. Lifespan Respite grantees could convene a Business Roundtable at the state level, with insurers, employers, managed care organizations, higher education, with other private and public sector entities to address respite workforce issues, paying for respite, respite for employed caregivers, and other important issues.
- Build and strengthen collaboration between Lifespan Respite grantees and State Medicaid agencies.*** Medicaid is the largest federal payor of respite for children and adults with disabilities, chronic illnesses and functional limitations, yet few states have engaged in meaningful partnerships to expand, enhance or innovate new respite

opportunities specifically for the Medicaid population. Similarly, State Aging, Disability, Public Health and Child Welfare agencies rarely collaborate with Medicaid to share strategies, respite best practices, data, or other useful information that could improve access to respite for both Medicaid and non-Medicaid eligible populations in the state.

- ***Prioritize, and provide resources for the development, improvement, and expansion of recruitment, training and retention of respite care workers and volunteers.*** Several avenues exist for states to pursue a stronger and more sustainable respite work force: 1) State and local agencies should implement the [National Respite Care Provider Training](#) for entry-level respite workers that was field tested in ten states – well-trained, well supervised and supported respite providers and volunteers are more easily retained over time; 2) To ensure that building, strengthening, and retaining a respite care workforce are included in discussions about solving the direct care worker crisis, Lifespan Respite grantees, partners, state agencies that fund or support respite, and respite providers, home care, faith-based and volunteer agencies in the private sector should be at the table in states that have direct care workforce task forces to address the broader workforce crisis; and 3) Capitalize on well-trained and supported respite workers and volunteers to provide an excellent pool from which to recruit direct care workers for career ladders in the professional direct care workforce.
- ***Build or expand state respite care provider registries that link trained workers to families searching for providers.*** Ten states have participated in piloting the National Respite Care Provider Training. However, those without well-established respite registries are struggling to match respite workers with families who cannot find respite providers on their own. Family caregivers also seek assurances that the respite workers listed are qualified, and that the respite care provided is safe. The NRCPT provides competency-based training that offers assurances to family caregivers that workers meet a basic, uniform set of [nationally-recognized competencies](#) for entry-level respite work.
- ***Identify and implement meaningful strategies to engage family caregivers from historically marginalized, underserved or under-resourced groups to share respite information and services.*** Along with educating and engaging the medical community, Community Health Workers (CHW) are an important resource in rural areas and may have access to VPNs and MiFi systems that would allow family caregivers to access online tools or forms and simplify submissions. Supplying them with resources for respite referrals and training them to help identify caregivers would improve their role in supporting Lifespan Respite programs. They might be able to complete assessments and even recruit respite workers. Other sources that would be helpful in expanding the reach to underserved family caregivers would include faith-based organizations, Tribal and other trusted community leaders, and 55+ active adult communities.

- **Ensure that when family caregivers receive financial assistance for providing care through Medicaid or other programs, they don't lose respite care eligibility and backup support.** Because of workforce shortages, many states have made it easier to implement self-directed programs which allow care recipients to hire their friends and family – an approach that the National Strategy supports. Unfortunately, this often means the overstressed and overburdened family caregiver is now hired to provide care, possibly as an employee of a provider agency, and paid for only a portion of the 24/7 care they are providing. They receive income but in some states, when family caregivers become direct care employees, they may lose their eligibility for respite services and other backup support.

ENDNOTES

ⁱ *The Shared Vision of Connecting Individuals and Families to Services and Supporting Family Caregivers*, ARCH Webinar, April 25, 2018. <https://archrespice.org/library/no-wrong-door-and-lifespan-respice/>

ⁱⁱ 1) *Nevada State Plan for the Support of Family Caregivers: January 2022 to December 2024*, <https://archrespice.org/nevada-state-plan-for-the-support-of-family-caregivers-january-2022-to-december-2024>; 2) *Rhode Island State Plan for Family Caregivers*, <https://archrespice.org/library/rhode-island-state-plan-for-family-caregivers>; 3) *Take a Break SC! Sustaining South Carolina's Family Caregivers through Respite*, <https://archrespice.org/library/take-another-break-sc-updated-state-respice-plan>; 4) *New York Lifespan Respite Final Sustainability Report 2022*, <https://archrespice.org/library/new-york-lifespan-respice-final-sustainability-plan-report-january-2022>.

ⁱⁱⁱ *Raising the Bar for Respite Through Coordination and Partnerships*, South Carolina Respite Coalition and the SC Department on Aging. PPT Presentation, 2024 National Lifespan Respite Conference, Albany, NY, May 22, 2024. https://archrespice.org/wp-content/uploads/2024/06/PowerpointRaising-the-Bar-for-Respite-through-Coord-Partnerships_SC_5.8.2024-002.pdf

^{iv} *Supporting Working Caregivers through Employer Engagement*, Panel Recording and Presentation Slides, 2022 National Lifespan Respite Conference, Madison, WI, September 15, 2022. <https://arch.wildapricot.org/Recorded-Plenary-Sessions-DAY-2/#Employers>

^v State Lifespan Respite Tools, See Employer Engagement Tab, <https://archrespice.org/ta-center-for-respice/state-lifespan-respice-tools-examples-by-category/>

^{vi} *Centering Equity in Access to Services: Lessons from the Field*, Lifespan Respite Washington, ARCH Webinar, June 8, 2023. <https://archrespice.org/lc-meetings/june-8-2023-centering-equity-in-access-to-services-lessons-from-the-field/>; *Including Diverse Communities in Respite Opportunities -- Lessons Learned from the Field*, Washington Aging and Long-Term Support Administration, PPT Presentation, 2024 National Lifespan Respite Conference, Albany, NY, May 22, 2024

^{vii} *Castig a Wider Net: Outreach Across the State of Tennessee*, Tennessee Respite Coalition, PPT Presentation, 2022 Lifespan Respite Grantee and Partner Learning Symposium, Madison, WI, September 13, 2022. https://archrespice.org/wp-content/uploads/2023/03/Breion_Dixon_ARCH-Bring-Brag-Borrow-2022.pdfhttps://archrespice.org/wp-content/uploads/2023/03/Breion_Dixon_ARCH-Bring-Brag-Borrow-2022.pdf

^{viii} Idaho Family Caregiver Navigator, <https://caregovernavigator.org/>

^{ix} Apply for State Lifespan Respite Voucher Programs, <https://archrespice.org/ta-center-for-respice/respice-voucher-programs/apply-for-state-lifespan-respice-voucher-programs/>

^x *Respite Care Funding for Tribal Nations of Wisconsin*, Respite Care Association of WI, PPT Presentation, Lifespan Respite Grantee and Partner Virtual Learning Symposium, May 8, 2024. <https://archrespite.org/wp-content/uploads/2024/05/RCAW-Bring-Brag-Borrow-002.pdf>

^{xi} National Respite Care Provider Training and Replication Toolkit, <https://archrespite.org/library/national-respite-care-provider-training-and-replication-toolkit/>