



## Lifespan Respite Grantee and Partner Learning Collaborative State Lifespan Roles for Implementing the Respite Actions in the National Strategy to Support Family Caregivers

Meeting Notes  
September 5, 2024

[Meeting Recordings and Resources Link](#)

### Announcements

- **Call for Presentations/2025 National Lifespan Respite Conference, RAISE & ENGAGE:** Launch Respite Now, April 1-3, 2025, in Huntsville, Alabama. The call for presentations is found at <https://archrespite.org/2025-national-lifespan-respite-conference/2025-call-for-presentations/>. Deadline to submit a proposal is October 1, 2024.
- **Call for Applications/Recognition of Innovative and Exemplary Respite Services:** a firm deadline for applications is October 8, 2024. Read more about the initiative, the selection process and how to apply: <https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/>. An Information Session Recording is available for review at <https://archrespite.org/library/information-session-for-2025-innovative-and-exemplary-respite-services-application/>
- **Virtual Respite Research Summit** will be held October 28-30, from 1pm-4:30pm ET each day. This free summit will include amazing presenters from the Committee for the Advancement of Respite Research at <https://archrespite.org/news-events/2024-resepите-research-summit/>. Register for the event at: [https://friendsnrc.zoom.us/meeting/register/tZYvduqtrDkoG9bnDiFSFhzLwWLZX\\_iHSQi8#/registration](https://friendsnrc.zoom.us/meeting/register/tZYvduqtrDkoG9bnDiFSFhzLwWLZX_iHSQi8#/registration)

### National Strategy LC Recognizes Participation

A sincere thank you was extended to all who have participated in this learning collaborative.

- 19 respondents to the National Strategy LC Feedback Survey
- 121 individuals (representing 29 states) participated in one or more of the LC sessions. A special shout-out to Rosalyn Alber, WA, and Lita Nelson, AZ, who both attended 13 of the 14 prior sessions.

- 25 Peer Mentors took an assignment to help with one or more of the LC sessions. These guest presentations from our colleagues were considered very helpful by 78.5% of the survey respondents.
- Susan Summers, Casandra Firman, Lisa Schneider, Cory Lutz, and Kathy Mayfield-Smith each facilitated some of our breakout sessions. Thank you, Jill Kagan, Meghan Kluth, and Cheryl Dinnell for making this learning collaborative possible.

## Introduction to National Strategy

The National Strategy to Support Family Caregivers was developed jointly by the RAISE and SGRG advisory. The Administration on Community Living (ACL) facilitates the work of the two advisory councils. They also administer the Lifespan Respite grants that support our activities. Almost three-quarters of the participants (73.6%) in the LC were Lifespan Respite Grantees and 36.8% were tied to the state coalitions.

The 2022 National Strategy to Support Family Caregivers 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. Awareness about the National Strategy was initially low as 42% of the LC participants indicated that they were not familiar with the goals, objectives or recommendations under the strategy.

Upon first hearing about the National Strategy in the launch of the LC, the most interesting goals for Lifespan Respite programs to focus on were: Goal 3: Strengthening services and supports for family caregivers, and Goal 5: Expanding data, research and evidence-based practices. Goal 3 holds the most objectives that respite is associated with, but all the goals hold some relevance to Lifespan Respite activities.

## Preparing for Leadership

In reviewing the National strategy, however, there were two main reactions: Excited, and Overwhelmed, even though participants saw that their respite grant activities had some or significant alignment with the National Strategy.

The question was: Is Lifespan Respite ready to take charge in leading out efforts on the National Strategy? While ARCH & ACL were confident, each Lifespan Respite program needed to look at how National Strategy goals and objectives fit into their state grant activities.

To respond to this question, 83% of LC participants completed a review of the National Strategy, 50% selected recommendations to work on, and 58% were engaged in conversations with others about implementation.

Also, after reviewing the Strategy, 33% of participants reported taking a leadership role on awareness and outreach recommendations, another 33% were working to strengthen services and supports for family caregivers, and 29% were working to build partnerships and engage family caregivers more. Building partnerships will likely be needed in all areas but special

emphasis on new partnerships and community connections would hopefully result from Lifespan Respite work on the National Strategy.

After attending the LC, 68% of the respondents said they gained significant improvement in understanding the content and purpose of the National strategy and felt their participation in the LC was valuable.

However, LC participants are juggling multiple activities and roles besides National Strategy implementation. 50% struggle with managing interruptions, 25% struggle to schedule time for it. National Strategy implementation feels like an “add-on” rather than an integral part of their work.

Although attending the LC made 42% of participants feel a lot more confident about their leadership role, 61% of participants said they were just beginning to work on motivational and educational interventions to prepare their state for change related to the National Strategy; 29% said they had progressed to working on enabling and skill building interventions to enact new practices around the National Strategy; and only 11% felt they had progressed to a point where they were reinforcing the structural and financing interventions to sustain changes aligned with the National Strategy (February 2024 - before states updated the matrix on activities around the National Strategy.)

Strategy implementation can be a prolonged process, and change occurs over time through three stages of implementation.

- 1) The first stage is motivational and educational interventions to prepare people for change. This stage helps “unfreeze” them so that they can move in a new direction.
- 2) The second stage is the enabling and skill building interventions to enact a new practice. This is the phase where people receive support for changing into the desired state.
- 3) Finally, we want to “refreeze” all the latest changes with process, structural or financing interventions to sustain change long term. “Refreeze” means to anchor or set the change permanently.

*Polling Question Results:* What is the status of any changes related to the National Strategy goals and recommendations in your state?

- 1) **Preparing for change**, through educational and motivational interventions? – 44.4%
- 2) **Enacting new practices of change** through enabling and skill-building interventions? – 33.3%
- 3) **Reinforcing infrastructure to sustain change**, through policy, structure, and financing interventions? – 22.2%

## Breakout Group Discussions

Breakout discussions were considered very helpful (at 63% of survey respondents). We are going to engage in some more group discussion today.

- How prepared and ready are you to take leadership on implementing one or more National Strategy goals in your state?
- What tools and/or resources would help you sustain your leadership efforts?
- We have explored many topics in the National Strategy Learning Collaborative sessions, but what additional information and/or support would be helpful to you as you continue your work?
- What else would you like to share about your experiences working on the National Strategy Goals?

## Ready & Prepared?

The Respite Care Association of Wisconsin looked at the various areas of activity they were engaged in through their Lifespan Respite grants and the 5 goals of the National Strategy and matched up all of their programs to where they fit into those goals under the National strategy goals. 90% of program activities fell within the 5 goals, including the data goals. Even though more heavily oriented to Goal 3, Wisconsin still sees a little bit of activity happening in almost each goal and can see what goals need more focus on as well. The same process was used with multiple organizations that are part of the coalition to recognize alignment with the National Strategy so now we have a document that shows we're all working towards the same common goals. Partners are picking pieces that they will concentrate on and taking roles that are moving us all forward together.

Washington State has embedded National Strategy goals in their grant applications to address strategies but has particularly been focused on revamping their coalition – to make it more robust with more providers and caregivers participating – to assure that caregiver voices are included. Washington also is working to better serve some target populations that tend to be more hesitant to participate in respite services.

Oklahoma is using the National Strategy as a guiding document to point out where improvements are needed. Having a National Strategy has bolstered efforts in the state because it supports why local and state leaders want or need to make these improvements. Oklahoma realizes that their senior population is higher than the national average. The state has taken leadership by passing a tax credit that will provide relief for family caregivers, especially those caring for veterans or individuals with dementia, demonstrating that there is some movement to support family caregivers that is not directly tied to the Lifespan Respite grant.

Illinois had many services and supports for family caregivers already built, and found they were strongly aligned with the National Strategy. A Lifespan Respite Taskforce, which meets monthly in committees, meets quarterly as a group and specifically works on Goals 1, 3, and 5 of the National Strategy. The committee reports at quarterly meetings have resulted in deep discussions around points such as "how do we really know who is underserved? Without a waitlist, how do we know how many caregivers are waiting for respite or other services?" With caregivers on the taskforce, Illinois is also beginning to reach Goal 2 objectives. As a participant

in the respite training pilot program, Illinois has been working on their trained respite workforce and is about 90% completed on the database, with a broad representation of caregivers ready to serve families across the lifespan.

Arkansas has new leaders who feel prepared to step up as needed but are hesitant because they recognize that there are aspects of their state internal system that they are not familiar with enough to project confidence in with regards to National Strategy implementation. Established leaders in Virginia and South Carolina echoed that they needed to be more familiar with the National Strategy as it is much broader than they thought it was and are grateful that the learning collaborative has recordings of past sessions to review. ARCH also offers one-on-one support to understanding the intent of the program and how states might fit into the effort.

Rhode Island is concentrating part of the state caregiver plan on gaining greater awareness of respite and other caregiver resources among professionals and BIPOC communities, especially in non-English speaking communities.

## Sustaining Effort?

For partners who are not the Lifespan Respite grantee in their state, it would be incredibly important for the state agency to come and sit down with partners to review these National Strategy goals and understand what the state is prioritizing, and recognizing and understanding what the coalition or other partners are doing, so that all of our work will mesh, beyond the relationship required for the Lifespan Respite grant application.

Even in states where there are frequent meetings between coalition partners and the lead agency for Lifespan Respite, partners may not feel empowered by the lead agency to help work on the National Strategy. One state leader found deaf and hard-of-hearing/blind and visually impaired groups wanted to talk about caregiving, and wondered how much outreach had been done before – maybe there has not been as much as there should have been. They had some resources to add online and are lending new thinking and perspective to the work.

Success can be a challenge. Even after establishing some strong core direct respite grants and specific targeting of certain populations that has resulted in exponential growth of programs, it is so hard to sustain a program when it is unclear if future funding will be for one year or three years, if even available at all. In moving forward on National Strategy goals, forecasting plans can only go as far as the funding, and results in a halting stop-and-start fashion for moving forward on objectives. Even states that have designated funding for respite instead of unfunded mandates, there are budget pressures and competing priorities that leaders must overcome. It works so much better when legislators with personal caregiving stories can be pointed to actions that will align with the National Strategy.

Over-reliance on federal funding for Lifespan Respite means states are not contributing to the funding of respite beyond match requirements, under the assumption that Lifespan Respite is getting sufficient funding from elsewhere. State legislators do not understand that national

funding is for very specific purposes, that state partners have core operations to manage. Even state agency heads have not advocated for increases in allocations for family caregiver supports and services. In this environment, what would happen without Lifespan Respite funding?

The RAISE and SGRG Advisory Councils can make recommendations as long as they don't call for additional federal expenditures,, which puts Lifespan Respite grantees and Coalitions in a unique position as they at least have dedicated respite funds to work with. Without additional funding, National Strategy implementation will be very difficult, unless Lifespan Respite programs can leverage their partnerships and think outside the box.

### Additional Information or Support?

With the National Strategy goals on financial and workplace security, Lifespan Respite programs would benefit from learning what others are doing to achieve these outcomes.

One place where Rhode Island has been getting good information is the ACL Technical Assistance grant which provides 250 hours of service. It has brought groups together weekly to share information on data collection around the direct care workforce and how it helps or hurts family caregivers.

Some expressed that knowing what direction people are going at the state level would be extremely helpful. Even if Lifespan Respite is just a cog in that big wheel, it would help Lifespan Respite leaders make overtures to others in different parts in government to see how they might work into the National Strategy too. What is being done on the National Strategy could be incorporated into a Master Plan for Aging, for example. It could be just adding a question to an intake form or looking at serving a slightly broader definition of eligible care recipients and family caregivers with services and supports.

A national campaign package for the National Strategy would be very helpful – like a pink ribbon represents breast cancer and everyone knows it. A national campaign will create recognition about how important unpaid family caregivers are – the backbone of our entire healthcare system. No matter how frequent the contact or how long the care recipient has been treated, no one ever asks family caregivers how they are doing.

What may be lacking is more teams within communities that can source out some of the activities that need to be done in National Strategy implementation, so that each agency isn't duplicating others' effort, trying to do it all alone, or just doing what they do really well instead of working on bigger goals together and networking so resources can be leveraged, maximized, or attained in other ways. When they apply for grant funding, some states try to find synergy with their partners on activities. If there are 5 different grants to fund outreach activities, this means additional staff, resources, and synergy may be found within programs so that everyone's efforts complement each other.

## Experiences with National Strategy?

Wisconsin notes that whenever the National Strategy comes up, people are interested and come to listen – because it is new, and they don't know much about it. For November during National Caregiving Month, Wisconsin will start training their Dementia Cares specialists, family caregiver support coordinators, and anyone else who is interested. Training materials and related information will be available online about supporting caregivers in the workplace – to ensure their financial stability, show employers how they can get involved and be supportive of working caregivers. One goal is to help people understand the demographics of society are changing, what it means to people in the workforce who are having caregiving stress and strain (that employers are largely unaware of), and how employers can help keep them healthy and working.

Rhode Island Office of Healthy Aging brought representatives from agencies in several fields together to begin to break down siloes. Nursing schools, social services, agencies that collect and analyze data, local charities, and many from different backgrounds provided an environment that was more accessible and diverse. Giving an opportunity to identify common goals and objectives that serve everyone at the table has created real partnerships and encourages other groups to join.

When new populations are identified, they are likely to be underserved. Approach the National Strategy goals strategically to see where they overlap with the new group's own goals or priorities. Where there is interaction between these two things, they are not likely segmented but integrated (like in a Venn diagram).

Whenever quality services and person- and family-centered practices are desired, training and support will be needed. There will not be quality without ongoing training of staff, especially where turnover in staff is high.

In Washington State, 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 pulling in every agency and program, including tribal people, that would have an interest in respite. It really involved a massive revamping of how to do things, with a lot of brainstorming about who should be invited across the state and pulling together a new mailing list of contacts. Now, small task groups have been identified and plan to meet, with high expectations for real change as more people outside of government get involved.

Wisconsin did a statewide survey, with two online versions (one for professionals and one for caregivers), to rank the National Strategy goals and provide feedback on what people would like to see implemented related to those goals. The surveys were disseminated from coalition board members to AAAs, across children's programming, to the ADRCs and counties - who then disseminated it throughout rural areas. Rural communities made it loud and clear that not everyone has access to the Internet, so paper copies did need to be provided. The data looks

interesting, as Goal 3 ranked highest for both professionals and caregivers. This will help Wisconsin put a plan in place on how to do better at supporting caregivers.

ARCH has a repository of information on surveys and other tools that might be helpful to Lifespan Respite programs. It is a good way to share and learn from one another.

Community Health workers (CHW) are a great resource in rural areas, because paper surveys are not always the best answer – there is too much room for human error and paper can get lost or destroyed. CHW staff may have access to VPNs and MiFi systems that would allow them to access tools or forms where tallies and analytics are done upon submission.

## National Strategy Goals

- ❖ Goal 1: Increase awareness and outreach to family caregivers.
- ❖ Goal 2: Advance partnerships with 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

Learning Collaborative Leaders' top identified barriers to implementation of the National Strategy were Resources (42%) and People (29%).

In looking at the National Strategy goals, discussion was directed at the challenges faced, the specific conditions required for success or movement on the goals, and what was gained from their experiences in implementing related strategies. What supports are needed to move forward? What recommendations should be shared with ACL? The chat function of the Zoom meeting was utilized to give everyone an opportunity to provide their thoughts.

**Lisa Schneider:** I think it's hard for Coalitions like RCAF (who are not the Lifespan grant applicants) to know exactly where the States are at, just know what we are doing at an organizational level. My two cents :) Anyone else feel this way??

**Cristina Amedeo:** Silos, having to compete for funding with community partners, buy in from partners, reaching caregivers not associated with community agencies. Judith Gaudet reacted with emoji.

**Tracy Kahlo** - Unpaid caregivers have overflowing plates and national funding so that when they move, they can access paid breaks. Judith Gaudet reacted with emoji. Toy Pilot reacted with emoji.

**Rosalyn Alber:** Finding resources/providers for isolated locations. Toy Pilot reacted with emoji.

**Tina Yurik:** one-sided partnerships.



**Lynn Gall:** Getting people who are dealing with so many issues to focus on only the National Strategy. The strategy is so large and contains so many recommendations, that asking for more than one thing at a time or educating about more than one component at a time becomes challenging.

**Denise Meza:** culturally and diverse messaging/outreach tools to reach underserved communities Tracy Kahlo reacted with emoji. Barb Koumjian reacted with emoji.

**Lynn Gall,** DHS: An additional person at the state level to work on implementing the National Strategy would be GREAT!! Lisa Schneider reacted with emoji.

**Lisa Schneider:** Federal funded programs address the gaps that result in people coming to RCAW even though they have federal funding, but it is not meeting their needs.

**Barb Koumjian:** Helping potential partners realize the value of a broad, state-wide coalition for policy change/creation.

**Judith Gaudet:** Though new to this, I would say increased advocacy for use and reimbursement for CHWs who can make connections in hard-to-reach populations that are culturally and linguistically appropriate. Jill Kagan reacted with ❤️.

**Denise Meza:** a public health campaign raising federal/state awareness on what caregiving is and put it on the zeitgeist of the public awareness beyond human services. Cristina Amedeo reacted with ❤️.

**Barb Koumjian:** and federal line-item funding for respite care, family caregivers are part of the health system. Cristina Amedeo reacted with ❤️. Tracy Kahlo reacted with ❤️. Lisa Schneider reacted with ❤️.

**Tracy Kahlo:** A national marketing campaign that we can use the items/tools and rebrand within our states to lighten our loads. Including data on what we're achieving, hearing from unpaid caregivers, etc. Cristina Amedeo reacted with ❤️.

**Barb Koumjian:** For the next iteration of the Strategy---for State-level suggestions, bring together action items for private/community sector and state-agency-level actions. Lisa Schneider reacted with emoji.

**Lynn Gall:** Like being able to prioritize at the state level, but what are the priorities for ACL beyond the five key goals? Would be interested to know what those initiatives are and if they are in the works.

**Dana Allard-Webb:** Not all cultures are ready to trust Lifespan respite outsider respite providers. Cristina Amedeo reacted with ❤️. Tracy Kahlo reacted with ❤️. Cristina Amedeo: So true Dana, I spent half of the morning talking about this subject at a Black Aging Resource fair. Lisa Schneider reacted with ❤️.

**Barb Koumjian:** Re: National awareness campaign—isn't there a TA Center funded through ACL that's supposed to be working on that? Denise Meza reacted with ❤️.

**Tina Yurik:** continue to expand state agency networking opt. Lisa Schneider reacted with emoji.

**Judith Gaudet:** Do most states have Community Advisory Boards? CABs are also known as public reference groups or stakeholder task forces. Tracy Kahlo replying - For Lifespan Respite WA <https://www.lifespanrespitewa.org/> we call it a coalition. Unpaid caregivers and professionals. <https://www.lifespanrespitewa.org/lifespan-respite-coalition/>

**Jill Kagan:** What about direct care workforce and building respite provider/program capacity? Lisa Schneider reacted with emoji.

**Lisa Schneider:** Bringing Respite to Your Community

**Lisa Schneider:** More focus on helping to develop respite programs in areas where it is needed. Tina Yurik reacted with emoji.

**Tracy Kahlo:** Our state DDA (Dev. Disabilities Admin) typically has funding options funneled through counties, other nonprofit orgs, etc. We utilized a 1-time \$50M grant opportunity to work with our camps for intentional DEI+B designed respite opportunities. Depending on funding we hope for options of up to 2-4 nights with each other and their loved ones.

**Rosalyn Alber:** The State of Washington Requires specific training to be an IP Respite Provider.

**Judith Gaudet:** Additionally, in most states the wait list for approval for employing family caregivers is 2 years or more.

### Recommendations

As a part of our report, we will include recommendations to improve respite based on the work of the Lifespan Respite Network. This LC session is an opportunity to introduce or emphasize National Strategy goals and objectives that Lifespan Respite grantees and partners would like to see reflected in the future work and priorities that ACL councils will champion. It will also provide some time to reflect on states' experiences and activities, identify gaps in the care and support of family caregivers, and suggest areas for improvement. The ARCH report on the National Strategy Learning Collaborative can then lend support to ideas and strategies that will improve future outcomes under the National Strategy plan.

In the materials generated from the LC sessions, several "wish list" items were identified that people felt could really lend to their efforts on the National Strategy.

- New people need to know how they can contribute but do not feel "up to speed," or even needed/acknowledged. Need to look for "shortcut" about National Strategy – a 1-page tool for onboarding so a first timer knows what is needed/how to help.

- Need to connect with faith-based, 55+ active adult communities, because they are already doing things connected to caregivers in those communities. Continue “old-fashioned” community events in rural areas where introductions, grassroots level stakeholder relationship building can happen “over a cup of coffee.”
- Strategies to break down local and state level silos (between agencies, geographic areas, etc.), Several states talked about efforts to reduce silos among partners due to different populations, funding streams, etc. across the lifespan. While some shared progress, this was recognized by many as an ongoing challenge.
- Building new partnerships, especially as a leader forging new partnerships outside the box. How do you do that? Business Roundtable at the state level, insurers, employers, private as well as public sector practices.
- In multiple ACL programs, there are commonalities among the strategies across these different programs. A “crosswalk analysis” would enable comparability not only between programs but across different activities. Figuring out how to address a particular strategy would be more effective in engaging others working on a similar strategy instead of “recreating the wheel” each time. It 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.
- Having heard of success implementing self-directed respite programs (that are often siloed in Medicaid or Managed Care systems), an important recommendation might be to look at those self-directed approaches more broadly – do caregivers really need to check a lot of boxes to benefit from this approach? Should programs for caregivers at least address why or why not a self-directed respite model does not work for providers or caregivers? A list of the reasons might clarify what the real barriers are to broader implementation.
- Finding a qualified respite worker through a registry is difficult for many caregivers – these online tools are difficult to navigate. Everyone wants to be patient- and caregiver-centered but there are so many different silo-based qualifications for providers. The pool of respite providers and the way providers/workers are recruited across Lifespan Respite programs could be more aligned. The self-directed hirer looking for a provider needs some consistency in the qualifications they are looking for, such as the respite worker training pilot program now available, and a simplification/streamlining of the process of eligibility tests and odd things caregivers are now required to provide or do. Shortening the period from “Yes, I’m ready to receive respite” to “Yes, I have received respite” means taking a fresh perspective on application, eligibility, documentation, matching and scheduling processes.

- Because of workforce shortages, states have made it much easier to take a consumer-directed approach which allows care recipients to hire their friends and family. The overstressed and overburden family caregiver is now made an employee of a provider agency and paid only a portion of the 24/7 care they are providing. They get some income but no breaks. The state has fulfilled its need for workers to provide needed supports, but its sense of obligation to supporting the caregiver/employee does not extend to ensuring they also receive respite services or even backup support if they are sick or need to take time off for themselves. In some states, when family caregivers become direct care employees, they lose their eligibility for respite services.

### Next Steps

***This learning collaborative was a beginning, not an end for Lifespan Respite leadership on the National Strategy.*** There will be a learning collaborative report that will be shared with ACL that includes recommendations to improve respite based on the work of the learning collaborative.

To view recordings and materials from previous meetings, please visit the [National Strategy LC webpage](#).

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