



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
February 1, 2024

[Meeting Recordings and Resources Link](#)

Announcements

The [2024 National Lifespan Respite Conference](#), *RAISE the Bar for Respite*, will be in Albany, NY on May 21-23, 2024. [Registration](#) is now open. Secure lodging quickly as the conference block of rooms will be gone soon.

A separate registration link was distributed for the **2024 Lifespan Respite Grantee and Partner Learning Symposium**, open only to grantees and their partners. Contact [Jill Kagan](#) if you did not receive an invitation to this event.

Please note the following scheduling changes for future **Learning Collaborative meetings**:

- **Volunteer and Faith-based Respite Learning Collaborative** rescheduled to **Feb 29, 2024** – Special Guest Speaker, **Dr. Fayron Epps, ALTER, Dementia-friendly Congregations**
- **National Strategy Learning Collaborative** rescheduled from April 4 to **April 11, 2024**

Principle of Leadership: Challenge the Process

As Lifespan Respite grantees and partners, we already have strategies in mind, at least conceptually, on how we plan to get from point A (where we are) to Point B (where we want to be). However, we live in systems, culture, and structures that can create barriers to our movement forward. Anything we do to improve or build on where we are will challenge the process, challenge the status quo. Removing obstacles empowers the people you need to execute your vision, and it can help the change move forward.

It is necessary to communicate that vision constantly. Implementing our strategy is how we aim to realize our vision. We aim to “change” something and change needs to be managed to be successful.

Ensuring that we are ready for change is also about removing or avoiding impediments that will halt or block change. We can expect resistance to change. Managing resistance to change requires you to first understand why people resist change, then identify the causes of their resistance, before implementing your strategy.

What consistently impairs implementation is simply not revisiting the strategy enough. This results in a loss of focus when the strategy is not front and center. Organizations and people move towards what they focus on.

Strategy implementation can be a prolonged process, so identifying tangible milestones, with definable indicators of results each step of the way will help you celebrate and record the progress from where you started to where you go.

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. People need the right environment for movement towards change.
- 2) The second stage is the enabling and skill building interventions to enact a new practice. This is the phase where we provide 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. “Refreeze” means to anchor or set the change permanently/

These three stages are effectively the path of all change.

Without motivation and commitment, getting movement from individuals on the desired change will be difficult. Without a vision, change will be disorganized and diffuse. Without the support of leadership and power players, change may be blocked or even sabotaged. Without a transition process, the team will have difficulty operating while moving to its future state. And without sustaining momentum, the strategy will not be able to bring the changes to completion.

Polling Question #1 Results: What stage of change are you at in implementing your National Strategy goal/priority right now? Are you working on:

- 1) Motivational/Educational interventions to prepare for change? – 61%
- 2) Enabling/Skill building interventions to enact a new practice? – 29%
- 3) Reinforcing structural/financing interventions to sustain change? – 11%

Studies show that only 5% of the workforce understands the strategy. Only 25% of mid-level leaders see any benefits or incentives linked to strategy. Reports state that 85% of executive teams spend less than one hour per month discussing strategy. A majority - 60% of organizations - do not link budgets or other resources to strategy.

Use the vision daily to make decisions and solve problems. When you keep it fresh on everyone's minds, they will remember it and respond to it. A vision for change is only as powerful as the communication that supports it. Communicate why the change is needed and provide a sense of urgency for the change.

Initiatives for change fail if people do not understand, believe in, or engage in the change. Leaders are up against company culture, organizational momentum, and human psychology when enacting change. Successful change management prioritizes people. People fuel change and sustain its momentum.

To be successful means knowing how to use your talent and resources to the best advantage. It is difficult to "win" if you do not have a game plan in place. Examine your resources, liabilities, capabilities, your strengths, and weaknesses through a [SWOT Analysis](#).

Polling Question #2 Results: Thinking about the implementation of National Strategy recommendations that you have adopted, what do you think is your primary barrier? Select the one that seems most applicable to right now.

- (1) vision barrier – 17%
- (2) people barrier – 29%
- (3) management barrier – 13%
- (4) resource barrier – 42%

The current state is how things are done today. It is the collection of processes, behaviors, tools, technologies, organizational structures, and job roles that constitute how work is done. The current state defines who we are. It may not be working great, but it is familiar and comfortable because we know what to expect. The current state is where we have been successful and where we know how we will be measured and evaluated. More than anything else, the current state is known.

The transition state is messy and disorganized. It is unpredictable and constantly in flux. The transition state is often emotionally charged—with emotions ranging from fear and despair to anger and relief. During the transition state, productivity predictably declines. The transition state requires us to accept new perspectives and learn new ways of behaving, while keeping up our day-to-day efforts. The transition state is challenging.

The future state is where we are trying to get to. It is often not fully defined and can shift while we are trudging through the transition state. The future state is supposed to be better than the current state in terms of performance. The future state can often be worrisome. The future state may not match our personal and professional goals, and there is a chance that we may not be successful in the future state. More than anything else, the future state is unknown.

Ultimately, you will be dealing with People Problems. People in management, people who control resources, people without the same vision, people just being people. Remember the old saying "People don't care how much you know until they know how much you care." How

committed people will be to solving problems with you could be measured by how you make them feel about themselves.

The most important questions people are thinking are: What does this mean to me; how will it impact my work? With a deeper, clearer understanding of the change, employees are much more likely to ask, "How can I help?"

There will be both high and low points during change initiatives where results do not measure up to expectations. During the high points of change, leaders should celebrate wins to fuel momentum. At the low points, leaders should use communication strategies to listen to employee input and reiterate the purpose and desired future state.

Nothing motivates more than success. You'll want to have some "quick wins " that your staff can see. Without this, critics and negative thinkers might hurt your progress. Create short-term targets – not just one long-term goal. You want each smaller target to be achievable, with little room for failure.

Finally, to make any change stick, it is important that your company's leaders continue to support the change. This includes existing staff and new leaders who come onboard.

Breakout Discussions

The purpose of the discussion groups is to find out how state grantees and their partners are dealing with perceived barriers to forward movement on the National Strategy goals and priorities they have adopted.

- 1) Describe a barrier you have encountered and share how you have overcome it. Did you identify your next steps with a "What would that take?" mentality?
- 2) Do you feel your vision and strategy align, given these barriers? If they do not, which one is more likely to change?
- 3) Can you describe "one small change" that has helped you move past a barrier?
- 4) Given the change you hope comes to fruition, what stage of implementation have you achieved?
- 5) How have the values of family caregivers and organizations that serve them helped inform the process?

In response to these questions, the following states reported:

Wisconsin reports that they are making progress with promoting the National Strategy goals through a hands-on effort in producing a working document that they will use to guide their work going forward. They report that having an existing and cohesive team has been an asset in their work, and they report that they are well on the way with a state strategy that matches their existing work toward building a strong state respite system with National Strategy goals.

New Mexico reports that their focus is on long-term strength-building of critical human infrastructure, especially respite education and training. They are encountering two challenges. The first is in human resources dedicated to leadership. Because hiring is controlled by the legislature in New Mexico, they are carefully crafting a position description for approval before hiring can be accomplished. The second challenge is engendering broad buy-in on strategic and sustainability planning.

Colorado reports that their vision is centered on increasing access to high quality respite services throughout the lifespan. Their definition of quality includes a strong focus on person- and family centered services, and they would like to increase innovation and collaboration around their self-directed voucher program as a strategy to achieve their vision. The key challenge they have encountered is a workforce shortage at management levels.

North Dakota reports that their vision centers on increasing access to lifespan respite. In their rural state, the respite voucher program is underutilized, and there is some ingrained, culturally grounded reluctance to using respite services. North Dakota respite has new leadership, and the breakout group offered support and resources to support North Dakota in finding ways to address these challenges.

Arizona has been working to reach and enhance access to respite services for populations throughout the lifespan, in addition to their ongoing focus and support for aging populations. Specifically, they are interested in entry into the respite system and making access easy and seamless for families. Arizona has made seed grants available for low-cost programs and services, and as part of those grants, is conducting an evaluation of the effectiveness of the referral process in order to better understand respite access. Arizona is also working with Arizona State University on a caregiver assessment tool.

More generally, the following discussion points are highlighted:

State Lifespan Respite grantees and their partners find they are not on the same page – with certain programs and activities aligned with the National Strategy struggling to move forward without the commitment and collaboration of the key players. Selling the vision and gaining greater buy-in will require more education and outreach, as newly established relationships help others care about having a role in moving forward together.

Funding and resources originally “promised” had seemed to reflect true commitment and support but were withdrawn because of competing priorities. American Rescue Plan Act (ARPA) funding is going away, and states are trying to figure out what readjustments post-Covid plans will allow. The question becomes “what can we do with what we have got?” and may require visions to narrow and strategies to take smaller incremental steps, while still getting some “wins.”

Getting caregivers involved in training and focus groups that might motivate them to make changes and share their voice about programming and goals has been difficult. Their barrier to

participation has now become the program's barrier to resolve. Several programs are paying them to participate, giving out gift cards, or finding other ways to engage caregivers but the results have been important. Getting their thoughts through surveys and focus groups, getting their buy-in on organizational vision, gaining their voice in advocating steps forward has proven invaluable. Deana Prest shared the results they gained in holding focus groups for caregiver input in New York in this report, [Caregiver Focus Group Report, 2021](#).

Making too many autocratic executive decisions, without taking the time to assess the impact of change and building from a place inclusive of others' thoughts and perspectives, slowed down change. Taking staff time away from work for team building might seem like an imposition, but the effort showed that people came, engaged, and the discussion was more important to team building than the topic discussed. Diversity/Equity/Inclusion topics were part of an AmeriCorps Challenge in January – timely for Martin Luther King Day – and led to reflecting/talking/thinking.

Internal changes may cause barriers - resistance to new leadership, the use of technology "improvements," etc. - impact how staff do their work, and how they interact with caregivers. Regular, frequent meetings to hear from staff about their feelings and experiences resulted in removal of unconscious bias, team building, opportunities to remind everyone about the vision and why their strategy aligns with that vision. Connect the vision back to the "why" the changes were made in the first place.

Guest Presentation:

Meeting the Mandate: How Arizona Overcame New Barriers

Lita Nelson from the Arizona Department of Economic Security (DES)/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.

As one of the first Lifespan Respite grantees, Arizona had a champion for respite in David Besst. He listened to caregivers, supported them, and advocated for them until his passing. He set a foundation for respite, including key deliverables: A caregiver assessment tool, a public awareness campaign, and a caregiver resource line.

A state statute in 2007 mirrored the Lifespan Respite Care Act and provided funding and staff to administer and develop a respite program, but without a champion, funding was frozen without advocacy for further appropriations. No one person, agency, or grant could really carry the work needed to support caregivers. There needed to be coordination among agencies, funding, stakeholders, to 1) strengthen strategic outreach to promote public awareness of respite and help caregivers self-identify, and 2) identify and engage stakeholders to address service gaps, waitlist, and staff shortages.

The Caregiver Resource Line, as part of their No Wrong Door system, has been successful in connecting caregivers with respite services, providers, and payment resources, while also identifying gaps in services.

The stakeholder outreach efforts resulted in the Arizona Respite Network, which has representatives from local, regional, and state organizations who have worked to 3) strengthen services and supports for caregivers by talking about who is doing what, identifying various payor sources, and looking for potential providers in rural/tribal areas.

The Respite Advisory Committee worked to develop a plan to address service gaps, and significant effort went into emergency respite services and community-based mini grants. Emergency respite and social day clubs were alternatives they wanted to develop, as well as unlicensed options outside of the provider network for respite services. They will be partnering closely with programs for adults raising children and grandparents raising grandchildren.

Aligned with the National Strategy goal to improve financial and workplace security, Governor Hobbs expanded paid family leave benefits to increase leave available for caregivers to use in care of others. The new Enhancement grant will aid outreach efforts, including development of a Resource Guide for Employers to increase outreach and to increase awareness of respite.

The Caregiver Assessment Tool is used by Area Agencies on Aging and the Arizona Caregiver Coalition to gather information on caregiver demographics and stress, while the Arizona State University will analyze the data, thus providing more basis for caregiver advocacy. They will continue learning from the caregivers themselves and where they experience barriers.

The Arizona Caregiver Coalition engages in social media, printed materials, and train-the-trainer programs to increase staff preparations, community outreach, partnerships, advocacy, diversity, and awareness initiatives. They are also actively involved in work on the strategic plan for Arizona family caregivers.

Next Steps

Next Meeting Topic. The learning collaborative will meet next on **March 7, 2024**, where the focus will be on **persuasion, power, and influence used to implement the National Strategy recommendations**. Power and influence can get others to act; power is based on positional authority while influence is based on relationships. Persuasion skills allow you to change or inspire another person's viewpoint by influencing them through verbal or nonverbal communication.

Soon we will be updating the matrix that we began at the start of the Learning Collaborative, entitled [State Lifespan Respite Grant Activities Aligned with the National Strategy's Goals and Outcomes](#), to see our movement on the goals and priorities identified as pertinent to Lifespan Respite.

Inviting Partners to Join the LC. If you have partners who are working with you on implementation of National Strategy goals that you would like to invite to participate in this learning collaborative, you may send [Jill Kagan](#) the names and email addresses of one or two key partners so that they can receive an invitation to join us in upcoming meetings. This is not an open invitation to all who you may be working with, but to a select few who you think would benefit from joining you in this learning collaborative.

Revised LC Meeting Schedule. Details on the framework, and the revised schedule for future meetings of the learning collaborative, are [available here](#). To view recordings and materials from previous meetings, please visit the [National Strategy LC webpage](#).

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