



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
November 2, 2023

Meeting [Recordings](#)

Announcements

The 2024 [National Lifespan Respite Conference](#), *RAISE the Bar for Respite*, will be held in Albany, NY, on May 21-23, 2024. Doris Green from the New York State Caregiving & Respite Coalition (NYSCRC) stated that they had received a ton of conference proposals which are in the process of being reviewed. She is excited about some of the keynote speakers who will be coming.

Principle of Leadership: 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 Learning Collaborative participants approach potential partners, they need to know how to develop a clear vision of their cause, and how they align with National Strategy recommendations. You, as a leader, must bring the vision of the National Strategy to life.

Research shows that “followers” respond to a leader who can articulate a vision that reflects the followers’ aspirations. Leaders are forward-thinking, forward-looking. This is a challenge because this leadership trait is something that new leaders may not have had to demonstrate in prior roles. Leaders need to get better at communicating an image of the future that draws others in and speaks to what others see and feel.

The only visions that take hold are shared visions. Leaders establish THERE – where we are going- and identify HERE – where we are now - and help the group or organization determine the right actions/strategy – which is the path to move from HERE to THERE. The difference between HERE and THERE must create the motivation to act.

An inspirational vision is one that taps into people's intrinsic motivation. Whatever the vision is, if people see and believe that getting there helps them increase or protect core motivations, they'll pursue it.

Vision casting is a method that most people think about when they think of inspirational leaders. Effective vision casting happens when a credible leader has a vision for the future that taps into the shared aspirations of others.

Vision gathering is a process of listening to the shared interests, aspirations, and concerns of others. Leaders then work with them to develop a picture of the future that meets those shared interests, aspirations, and concerns.

To effectively inspire a shared vision and lead it to reality, leaders need three things: Credibility, Shared Aspirations, and Ownership.

Watch out for vision killers. Effectively, that is anything that stops us from moving forward in pursuit of our vision. Sometimes we must let people go off the team. When we ask someone to leave the team, we are not saying that they are unprofessional, or incompetent, or any other such thing. We are acknowledging that they don't share the same vision with us! A group cannot pursue a vision without everyone being onboard.

To put a vision into action, leaders must continuously work to build clarity around the organization's message. As we implement elements of the National Strategy, all of us need to be out there, stating, clarifying, discussing, modeling, filling the space with the messages we care about.

Poll Question

Taking leadership to implement a goal/recommendation from the National Strategy is the role we hope you will assume. The polling question will give us an idea of what area of the National Strategy to Support Family Caregivers is gaining your greatest interest. Responses to the polling question are included below:

Given your own review of the National Strategy, and for the purposes of this learning collaborative, where are you planning to put your leadership effort?

- Awareness & Outreach - 33%
- Build Partnerships and Engage Family Caregivers – 29%
- Strengthening Services and Supports – 33%

- Financial and Workplace Security - 0%
- Expand Data, Research, and evidence-based Practices – 5%

Breakout Discussions & Group Report

The purpose of the discussion groups is to find out where we all are in developing a **vision** around the National Strategy.

Discussion Questions:

- 1) Do you have a **vision statement** for your efforts aligned with the National Strategy? Tell us the area of interest for your leadership and talk about your vision of the future. If you have a statement, picture a friend or family member asking: “what does this actually mean?” Does the message get across? Is it inspiring?
- 2) The real stakeholders in your vision are likely a diverse group of family caregivers, with unique perspectives on what they want your efforts to “look like.” You are leading the way to making their dreams come true. How are you making sure that the vision you propose fits with the outcomes they want to see?
- 3) Vision is like a magnet, as it draws people in and pushes others away. How do you know if you have core people engaged in your vision who really care? If they don’t, what are you going to do about it?
- 4) November is **Caregiver Awareness Month**. What are you doing to help recognize and support family caregivers? Are there any activities happening in your state or locality this month?

Very few participants said they had a vision or a statement about their vision – especially not ones tied to the National Strategy. Some realize that they need to do some work to craft a vision or elevate what they are already doing into a vision statement, but many feel they are addressing the National Strategy recommendations/goals through the robust work they have been doing, in some cases for over a decade. If they have vision statements for the programs and activities they already have going, they need to review it so that it brings people together, strengthens the system of services, and encourages alternative approaches to respite services and resources. Many in the groups seemed to agree that there is a lot of work to still do when it comes to talking about what things “will look like” and developing messaging that supports that vision.

Several people mentioned the effort to “beef up” their coalitions, bring in caregiver voices, and organize workgroups/commissions who will then be developing the vision for the work going forward. A lot of times, it’s educating partners/agencies about family caregivers.

Many leaders are aware of the National Strategy and are keeping it in mind as they look at expanding, enhancing services. Strategic alignment with the National Strategy has been an internal review before going outwards to gather stakeholders and community partners.

Those who have data/past surveys on caregivers – after asking caregivers the right questions – feel that they know the needs/gaps and can advocate on behalf of caregivers, even if they are not at the meeting. Those caregivers’ voices are represented. Getting to caregivers relies on a good marketing plan and may require connections through Facebook groups and other venues. People are looking at public schools, childcare providers, and other partners who can lead them to caregivers. The challenge continues to be caregivers who don’t identify as caregivers – since they are not “a paid person” or do not work in a care facility. Most leaders do have some degree of input from/assessment of caregivers’ needs, through listening sessions, needs assessments, or person-by-person engagement. These contribute to a “sense” of a vision for how to move forward in the work.

Some efforts such as conferences, retreats, and summits have brought caregiver voices into the discussion and planning. Programs have made it easier for caregivers to participate, by offering travel/lodging, respite, stipends, and other incentives. Caregivers were encouraged to “ring bells” if speakers/participants used jargon and alphabet-soup labels that made it hard to follow dialogue. Facilitators help to call on them and ask for their thoughts. In collaborations, leaders are asking caregivers to contribute by doing what they want to do and in a way that they can, rather than assigning them to roles. They strive to make sure everyone feels valued for their contributions.

Some recognize the need for multiple messages, targeted to specific sectors of the population. With multiple tribal nations, large populations of retirees, “snowbirds” who come and go during the year, refugee groups, and long-distance caregivers all have different needs, different perspectives, and require long-term engagements to build trust and rapport.

Collaborations are valued, as people reported that “collaboration is our middle name” and that leaders don’t do anything by themselves. It is important to consider everything together. Building a vision together is important when picking priorities – not any one organization can really take a bite out of the goals themselves.

Guest Presentation: *Looking Forward - Implementing the National Strategy to Achieve New York's Vision*

Presenters from the New York State Office for the Aging, **Deana Prest and Abbey Derepentigny**, and **Doris Green** from the New York State Caregiving & Respite Coalition 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.

Every year, they engage in sustainability planning and develop their strategic planning logic model to expound their vision: Supporting New York's Caregivers. The success of their plan would encourage innovation and decrease caregiver burnout.

While their process involves several aspects, this presentation focused on the area of exploring collaboration opportunities. With their core partners from NY Office for the Aging, Respite & Caregiving Coalition, 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. Keys to their successful collaboration have 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 their strategic plan. This collaborative approach also is applied with other partners in the state.

The collaborative approach has ensured that each program is considered in the various projects each undertakes. For example, New York uses TCARE as their caregiver assessment tool under the National Family Caregiver Support Program and is piloting that tool through regional caregiving wellness and respite centers, an arm of the Respite Coalition. This evidence-based tool used consistently gives them data from across the state and may lead to opportunities to work with the AAAs in the counties, overseen by the Caregiver Wellness and Respite Center.

Monthly webinars are offered at local offices for the Aging, where the Respite Coalition is invited to share updates on what they are doing and any upcoming events such as conferences or training that might attract caregivers – expanding the awareness of caregivers and their needs.

As New York worked to expand caregiver-directed respite, a workgroup was formed under the National Family Caregiver Support Program to look at creating options for respite – and the use of respite vouchers – so the Respite Coalition was included to learn what the

AAAs and caregivers thought would be beneficial. NY county AAAs could use the Respite Coalition as a fiscal intermediary for the respite voucher program.

Strategic planning retreats held annually since 2018 help the team work on their sustainability and logic model. Statewide Sustainability Summits provide an opportunity for state representatives and family caregivers to exchange knowledge and expertise. The most recent summit was focused on developing an advocacy strategy to strengthen the respite system.

Caregiver Forums have also been held to engage caregivers, the public, and staff who administer or provide caregiving services so that greater understanding can be reached on the support services available and how they could be expanded and enhanced.

New York was recognized in receiving the Pacesetter Prize in 2020 for their comprehensive approach to empowering family caregivers across government programs and agencies, which has given them the motivation and empowerment to keep moving forward – despite all the hard work. From their start with one or two efforts in the early years, legislation, organizational development, grants, and greater opportunities have come their way. Funding has increased from some sources and has been stagnant in others, but overall, New York has made an explosion of activities and tremendous progress in their vision of supporting family caregivers.

Deana says that every single time they are working on a project in her office, no discussion or planning is approached without having the Respite Coalition and other partners in mind. Talking it through with other leaders who are not involved in respite and caregiving and who don't know what is needed, it is up to them to be the advocate and bring to others' attention ways to structure services to benefit the state and be more inclusive of these partners. Many times, she is knocking on the doors of her core team members, encouraging them to work together on new initiatives. They can flourish and grow by building new blocks on the foundation they've built together.

Regarding the National Strategy, they had their MSW student intern look at the strategy and compare it to New York's current activities and develop a chart to see what they are already doing and identify gaps and where they could grow. When the Master Plan for Aging Executive Order launched, Deana was asked to co-lead the informal caregiver subcommittee. Workgroups were organized for specific topics, so Deana asked her core team partners to join these workgroups. Some of the pillars of the Master Plan have tied informal caregiving to workforce issues and that's not exactly what they wanted to see. So, they spoke up to have informal caregiving as its own pillar, and now changes in the Master

Plan will be made that reflect the voices of these advocates. The NY National Strategy chart has aided a lot of workgroup discussions – in showing these “new” partners the work that has been done and how there’s still work to be done. Even the great work done could benefit from more funding - so that support is available to more caregivers.

Having a vision, having something to tap into, has been amazing for the Coalition in finding some additional funding opportunities. Deana expects to see more successes in the future.

Doris says Deana is very skilled in visioning and it results in a lot of work! All the National Strategy goals have been put into one of the four workgroups under the Master Plan for Aging: Caregiver Supports, Kinship Caregiving, Communication Strategies, and Finances. There were a lot of overlapping issues in all these groups. So, Doris got the leads of all the workgroups together to talk about these overlaps. The results were that the first recommendation made was supported by all the other groups – 100% said they backed getting a governor-appointed caregiver coordinating commission. The National Strategy recommendations are also being looked at in the development of the Master Plan for Aging.

We have this Hub & Spokes model dream for Caregiver Wellness and Respite Centers but need to identify partners who could do this work in various parts of the state. People running the ADRC in more rural areas seemed to be perfect partners to approach. Now they are serving caregivers across the lifespan, not just Alzheimer's families. They hope to build this throughout the state because the regions of the state are very distinct and diverse.

Using an AmeriCorps Seniors grant, the NYSCRC is working to attract seniors/older adults as respite providers in rural areas. They hope to ultimately move them into the workforce – at least 30% of the people they engage as volunteers under their grant.

The idea for a Caregiving Coordinating Commission came about from reviewing Alabama and Maryland’s approaches. Discussion now is on who is going to be on the commission; leadership from across all the government agencies is the hope. They really want to coordinate statewide planning, development & implementation – in part to avoid duplicating services and fighting for resources.

Chat Report on Caregiver Awareness Month Activities

Marilyn Sword: In Idaho, you can see from my virtual background that we are all using a message about Family Caregiver Month, plus we have the Lt. Governor signing a proclamation and are posting daily social media posts regarding family caregiver month. In late October, we conducted a 3-hour training on advocacy by telling your story to policy makers; this was done in collaboration with AARP Idaho and our southwest Idaho Independent Living Center. That training is available on our website. We are working with a cross section of organizations on the direct care workforce shortage and, from our perspective, the impact of that on our family caregivers.

Jenny Andrews, SCDOA: South Carolina has a proclamation from the Governor for Family Caregiver month. There will be a press release and social media engagement with that proclamation. We have a virtual caregiver conference scheduled. Two of our AAAs also have a caregiver event planned. We are working on social media posts regarding National Family Caregivers Month.

Next Steps

The learning collaborative will meet next in December 2023 (date to be determined), where the focus will be on partnerships and enabling others to act on National Strategy recommendations.

Learning Collaborative participants will learn 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(s) is a critical element of successful campaigns promoting the National Strategy and its proposed actions.

If you have partners on achieving 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 a select few who you would benefit from joining you in this learning collaborative.

The framework for the collaborative has been outlined in a schedule of upcoming meetings and topics found at: <https://archrespite.org/wp-content/uploads/2023/10/Frameowrk-for-National-Strategy-Learning-Collaborative.pdf>

If you missed any meetings, please consider viewing the meeting recordings or reviewing the notes. These can be found on the ARCH website at <https://archrespite.org/ta-center-for-respite/learning-collaboratives/#LCAdvancedTabs-5>.

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