



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
October 5, 2023

Announcements

- RAISE Family Caregiving Advisory Council Meeting, [September 18, 2023](#). Lynn Gall, Family Caregiver Support Program and Lifespan Respite grant Manager, the WI Department of Health Services was appointed.
- One year anniversary of the National Strategy. A milestone [video](#), *Year of the Caregiver*, released by the National Alliance for Caregiving. [ACL awarded funds](#) to four national organizations to assist Aging Network in implementing 4 of the 5 strategy goals. ARCH is a named partner with USAging to implement Goal 3 on services and supports.
- [Caregiver Nation Summit 2023](#), October 25-26 in Washington, DC. Advocacy skills training and opportunities to visit legislators led by ACT on RAISE.
- NASHP's new website, [SupportCaregiving.org](#), will simplify the National Strategy for all audiences, and help people understand what is in it and how it can be implemented.
- New Respite Care Resource Guide developed by ARCH in collaboration with NASHP available, targeted to Medicaid and other state agencies to help implement National Strategy. <https://supportcaregiving.org/respite-care/>
- Call for Presentations deadline is 10/30 for the 2024 National Lifespan Respite Conference, *RAISE the Bar for Respite*, to be held in Albany, NY, on May 21-23, 2024. <https://archrespite.org/2024-national-lifespan-respite-conference/>
- Lifespan Respite Grantee & Partner Learning Symposium will be held May 21, 2024, in conjunction with the National Lifespan Respite Conference.
- Introduction of Cheryl Dinnell as the new facilitator of the National Strategy Learning Collaborative. A new [framework](#) for the learning collaborative will focus on leadership skills towards the implementation of the National Strategy.

Principle of Leadership: Model the Way

Participation in this learning collaborative assumes that the National Strategy for the Support of Family Caregivers includes some recommendations you want to see implemented. You have the gifts and talents that can be employed in moving forward; you are coming here to learn – that you are open to new ideas, willing to test them out, and grow in your own skills & abilities; and you recognize that people are the most important resource, in realizing the future we hope to see. You are a catalyst for change - to bring the vision of the National Strategy to life.

Discussed the traits of high performers to see if our leadership efforts share these traits in common. Leadership is about redefining things, finding new solutions and leading others to bigger and better things. Leadership isn't a position of power, but it is powerful! Managers make sure that things are done the right way, but a leader makes sure we are doing the right things to achieve the identified vision.

Poll Question

Since learning about the National Strategy for Support of Caregivers, where are you at currently in implementation?

- 83% have completed a review of the recommendations in the National Strategy.
- 50% have selected recommendations for new or continued effort.
- 58% have had conversations with other leaders about implementing recommendations.
- 17% have formulated plans and agreements with others on working together.
- 0% have taken steps forward in implementing plans for the National Strategy.

Breakout Discussions & Group Report

The purpose of the discussion groups is to find out where we all are in implementing recommendations of the National Strategy.

Discussion Questions:

- 1) What is your state's buy-in on the National Strategy currently? Are you yourself a champion for implementation on any National Strategy recommendation in your state? Why or why not?
- 2) How would you describe your role/identity related to the National Strategy? What do you need to do next? Assess the need for change, develop a plan, delegate tasks, decide on timelines? What is stopping you from moving forward?

- 3) Are you cultivating other champions? Do you have enough people joining in the effort? How are you encouraging the involvement of others? Are they connecting in a way that their hearts are involved?
- 4) Does your state (or other leaders in your state) have competing interests, concerns, or priorities? Who are the credible voices who have been most effective in bringing their issue(s) to the forefront? How can you benefit from/leverage their expertise in promoting their issue(s) successfully?

Some people were part of the conversations around the National Strategy, but others were not at the table to discuss implementation. Some states have state plans that align with the National Strategy and are embedded in everything they do, but others see siloing of funding and who is served, or limit their partnerships with the state to avoid regulations and requirements that make it difficult to offer services and combine resources. States have taken time to make sure their priorities align with the National Strategy or find that many of their activities already do align so they are continuing their efforts. Some multi-state efforts are targeted to serving tribal communities under one National Strategy recommendation. As things move along, programs hope to incorporate more of the other recommendations and strategies.

There is a lot of work to be done and many competing priorities, such as crime, 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 do not always let ideas move forward. One state is planning subcommittees with a focus on their own target population and activities, rather than bringing a group around outreach & awareness, employment or education, or expanding services. They are hoping to get more interest and participation in targeted groups, but with each group having multiple goals in mind.

Some programs have a dedicated person working on National Strategy recommendations. Others are looking down the road for leaders, not just who they need now but those who will be needed in the future. Some are struggling with staff transitions and new people coming in.

They are focusing on new partnerships and outreach to bring new members into their coalition. There are potential partners who are not involved yet, such as Department of Education, CDC, Department of Labor, Workforce Development, Disability Councils, and others who need to be approached. Some states have worked with their AAAs and several agencies in government to look at the goals and strategies and consider what

they could do. They are looking for ways to build in equity and inclusion goals - working in silos yet also knowing what other organizations are doing to avoid duplication and learn from each other. It is better to include others before, rather than after the fact.

Awareness is still a challenge to have family caregivers recognize themselves as such. Working professionals are also called caregivers. So much has been going on that it is difficult to make progress forward. Some programs have recognized that they haven't done much with working caregivers and see that as a place to start. Others are trying to approach MCOs and Health Care Authorities to help them define caregivers and offer certain options and resources.

They have found gaps that need to be addressed, are engaging in legislative activities, and keeping their groups informed about efforts around the state. Specific interest was in sharing data with the goal of identifying where the gaps are – in underserved populations and counties. Respite provider training was leading to efforts to develop respite registries to provide additional support to family caregivers.

Guest Presentation: Outreach to Spanish-Speaking Populations

Presenters Adrian Rodriguez and Sheila Weaver from the Idaho Caregiver Alliance spoke on their outreach to a large population that they were missing. It began with a simple conversation about "how could they know of complaints" from Hispanic community when there was not a form in Spanish that they could use. They had to consider how mindful they were in engaging the Hispanic community.

They adopted the goal of ensuring accessible and culturally appropriate information and resources across the lifespan, by forming an advisory committee around partners, caregivers, and members from the Spanish-speaking community. Through those relationships they were able to get funding to diversify their staff to include Spanish-speaking navigators. Previously they thought their services were "available and accessible" but it was only "available" - it needed to be accessible to this population.

Prepared materials were targeted to Hispanic community and distributed through the partnerships created in our coalition.

One question was about 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. They

share others' posts, and these people and organizations returned the favor and share posts generated by the Idaho Caregiver Alliance.

Idaho has a Mexican Consulate to partner with, and giving presentations to organizations or participating in conferences connected to the Hispanic community has been a way to physically be present in face-to-face interactions with the community.

When presenting their programs, the Idaho Caregiver Alliance always includes strong representation of the Hispanic population and culture in slides. Representation includes understanding the unique needs of Hispanic caregivers, plus recognizing the diversity of the families served and their intersectionality with other groups of caregivers. Profiles of family caregivers put a "face" on what Hispanic caregivers are like.

Because of the Idaho Caregiver Alliance's work in the Hispanic community, they were given funding to do research on Hispanic caregivers and Hispanic communities in general. What they have learned from that research is now used when they are engaging the Hispanic community and continuing to develop and improve their programs. Finding out what influences the use of their services among Hispanic caregivers, and what is behind the utilization of public health and social services, means making services culturally relevant. Barriers in the Hispanic community include strong cultural values, such as the strong interdependence towards family and close friends. Trust is necessary to break into these networks because programs are not engaging the individual but a family unit. Going to seek services may not jive with Hispanic cultural values surrounding the male and female role. It takes time to honor the dignity of and develop respect among the Hispanic population. Even talking about a diagnosis might take away from a person's dignity. Cultural literacy is more than just translating from English to Spanish.

It is important not to go into a community with an agenda, but to ask them to identify their own needs, barriers, and experiences.

Making little steps along the way has added up, and they make sure to celebrate and recognize their accomplishments. In 2016, there was nothing in their strategic plan about this outreach effort.

It began with a conversation. Gaps were recognized, and an internal evaluation conducted. An advisory group was formed. This led to diversified staff and targeted marketing materials. Activities and partnerships led to networking, research and successful outreach that have cemented relationships going forward.

Next Steps

The learning collaborative will meet next on November 2, 2023, where the focus will be on visioning the future based on the National Strategy recommendations. 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>

→ ACTION STEP

Because there are so many recommendations, please select one of the recommendations to tackle first and review the ARCH Learning Collaborative site for recordings and resources related to the National Strategy for the Support of Family Caregivers: <https://archrespite.org/ta-center-for-respite/learning-collaboratives/#LCAdvancedTabs-5>

Prepared by ARCH for the Lifespan Respite Grantee and Partner Learning Symposium on Implementing the National Strategy to Support Family Caregivers, October 2023

This project is 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.