

Lifespan Respite Grantee and Partner Learning Collaborative on State Lifespan Roles for Implementing the National Strategy's Respite Recommendations Meeting Notes

June 15, 2023

2:00-3:30 pm EST

[Meeting Recordings](#)

- **Welcome, Introductions, and Overview of Agenda - Meghan Kluth**

- **Upcoming NASHP Webinar - Jill Kagan**
 - NASHP is hosting a webinar later this month called Emerging Respite Care Strategies in Medicaid Home and Community-Based Service Waivers
 - Thursday, June 29, 2023 - 3-4 pm ET
 - Registration: https://nashp-org.zoom.us/webinar/register/WN_LwbVkJMubTLqmiQLkUYfywA#/registration
 - Resource: Highlights of key takeaways from a [new NASHP report](#) that explores Medicaid waiver HCBS waiver respite best practices for older adults, adults with physical disabilities, and their family caregivers

- **White House Executive Order on Increasing Access to High Quality Care and Supporting Caregivers - Jill Kagan**
 - This spring the White House announced more than 50 executive actions across multiple agencies under the following broad topics:
 - Increase compensation and improve job quality for family caregivers and care workers
 - Make care more accessible and affordable for families
 - Expand options for families by building the supply of care

 - ARCH released a new resource that summarizes the respite related elements on the executive order
 - ***Highlights of Important Actions for Respite and Support for Family Caregivers*** in the White House Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers
<https://archrespite.org/wp-content/uploads/2023/06/Highlights-of-Important-Actions-for-Respite-and-Support-for-Family-Caregivers.pdf>

 - Group Discussion Question: How do you anticipate the executive orders will impact lifespan respite efforts in your state?

- Nevada: Nevada’s Medicaid program is doing a rate study on Medicaid funded programs. The NV Lifespan Respite Coalition is particularly interested in seeing the results for respite care and related services. That could be tied to increasing compensation within the workforce. The state has also submitted a new proposal for Home and Community Based Waivers to CMS to explore possible adjustments with their package of services.
- Discussion about expanding VA eligibility: ARCH is not yet aware of details on this within the executive actions but will be following it closely. The Program of Comprehensive Assistance for Family Caregivers is now open to veterans of all eras but it can still be difficult to navigate the eligibility requirements. The executive order specifically talks about expanding the veteran-directed program to more sites.
- Illinois: There is currently a proposal to increase wages for direct service professionals. The Illinois Pediatric Palliative Care Coalition was successful in its efforts to secure Medicaid waiver funding for respite starting in 2024. Illinois Respite Coalition is finishing up a year of work with ARCH, NASHP and the Respite Care Association of Wisconsin to pilot the entry-level respite provider training curriculum. Following up on this effort, they are developing a respite registry to make the list of trained providers available to family caregivers, and also working to make the training accessible to people with disabilities.
 - This was part of a field test of a competency-based respite provider training led by ARCH, NASHP and Respite Care Association. ARCH and partners are currently analyzing data from this work and developing a replication toolkit.
- Washington: Washington partners with an organization called PAVE that houses Lifespan Respite Washington. When they received the AARP information for states about direct care workers and family caregivers, they knew their rate had gone up to \$21/hour. This is the highest in the country for direct care workers, as well as good benefits. However, they are still seeing workforce challenges. The training division of ALISA is bringing interested parties together to brainstorm how to attract more direct care workers. They are developing a new toolkit of successful recruitment and retention strategies for managers and supervisors of home care agencies, assisted living facilities and other providers. Additionally, WA is working to

increase their tribal outreach within their respite voucher program.

- **Lifespan Respite Grant Proposed Activities**

- Congratulations to those who recently submitted grant applications!
- Group Discussion Questions:
 - How do your proposed activities in response to the most recent funding opportunity announcement align with the national strategy?
 - Have you proposed or considered convening a stakeholder group to address the goals and actions in the national strategy?
 - Illinois: Illinois is now in their third year of their lifespan respite grant and are now in the process of creating a statewide respite task force. The timing couldn't be better and it's great to see the pieces coming together. They hope to make it a quarterly meeting structured. As applications have been submitted, the Coalition is excited to see a diverse group of representatives from across the lifespan. Almost half of the applicants are family caregivers.
 - Idaho: Idaho partnered with their Division of Public Health for their proposal. This is a shift for the latest proposal and is a win-win that opens the door for a variety of new partnerships and collaboration across the lifespan. They hope this will increase their relationships within behavioral health and Medicaid.
 - Wisconsin: Wisconsin held their annual respite summit earlier in June. They brought a large group of attendees from across the state together. Several providers and prospective providers attended to learn more about respite, reopening adult day centers, etc. Some of these are new players, which is exciting. There seems to be growing interest in providing respite and making connections with the Respite Association of Wisconsin and their available resources.
 - Wisconsin: The Wisconsin Family Caregiver Alliance, a diverse group of organizations advocating for caregiver supports and of which the Lifespan Respite grantee and the Respite Care Association of WI, is reviewing the national strategy to determine which areas are reasonable and make sense for their network to work on and weave within their collective goals. They have focused on what they can realistically have an impact on and are now working on how they can implement these ideas.

- Nevada: Like other states, Nevada has seen challenges with siloed work. Following the passage of recent legislation to pilot caregiver assessments, NV Lifespan Respite Care Coalition is using this momentum to see how they can engage more partners and set up agreements for ongoing collaboration. They are also looking at how to better utilize the state's No Wrong Door system and 211 to better support family caregivers.
 - Illinois: The Illinois Respite Coalition is partnering with a new Illinois Caregiver Coalition run out of the Department on Aging to better align their respite actions.
- **National Strategy Goal 3: Strengthen Services and Supports for Family Caregivers**
 - We broke into breakout rooms to discuss several questions about states' strategies and activities related to Goal 3. We will continue this discussion at the July meeting.
 - Discussion guide: <https://archrespite.org/wp-content/uploads/2023/06/Revised-Breakout-room-discussion-guide.pdf>
 - Breakout Room Discussion Summary:
Which Goal 3 outcomes have you focused most on in your state in recent years?
What would you like to expand, explore further, and/or tweak?
 - Texas: The TX Lifespan Respite Program is run through a network of 28 ADRCs across the state. Texas did a needs assessment and provider surveys across the state for respite. They learned they need to do more marketing to help people understand what respite is. Some ADRCs are performing very well with respite, and others are not or are in the middle, so they are encouraging higher use of respite dollars. Texas would like to do more with respite provider training.
 - New York: New York cross walked the national strategy outcomes with their efforts. They are doing well with Outcome 3.2 (respite strategies that meet the unique needs of caregivers). They recently expanded their caregiver-directed respite model to Area Agencies on Aging under the National Family Caregiver Support Program and will allow in-home and out-of-home care and vouchers. There is a very big faith-based respite community in western NY with 30 drop-in respite centers. They are piloting a Caregiver Wellness and Respite Center in northern NY that provides education and respite for caregivers.

New York is working on a master plan for aging. There are several work groups meeting regularly right now on this to focus on caregiving issues from

awareness and communication to financing to supports. The Lifespan Respite grantee and NY State Caregiving and Respite Coalition serve on workgroups that are developing the plan. They will use the cross walk/matrix of national strategy outcomes and respite actions to inform the work on the master plan and assist with funding requests. They will other workgroup member add to it the matrix. This planning effort will be very helpful in sharing strategic planning with their partners across the state and to help identify gaps.

- Nevada: Many of their activities fall within Goal 3. Sustainability has been one of the biggest challenges. Nevada's grant is now housed in the Aging and Disability Services division, which has been helpful for funding, support, and collaboration. They found through their voucher program that it was difficult for families to find providers and participated in ARCH's pilot (referenced above) to increase training for the direct care workforce in the state. Several programs have closed as a result of COVID-19, including respite as well as related support services for caregivers.

The focus is on rebuilding. As a starting point, the NV Lifespan Respite Care Coalition prepared a [Nevada State Plan for the Support of Family Caregivers](#). Their team has shifted focus to how to support startups and new businesses entering the field to help them get up and running with Medicaid rate efforts, navigating licensing, etc. The state passed legislation to pilot use of caregiver assessments with partners to improve overall understanding of what caregivers need. It's been hard to get people engaged in this process, but recent legislative support has helped. In addition to these specific activities, they are continually working on keeping the coalition strong and together to keep the work going.

- Follow up discussion on caregiver assessment efforts: Texas shared about the impact of bringing in local data from health policy experts at Texas A&M University that further legitimized the effort. This helped people see the data is a more meaningful way versus national reports.
- Colorado: Colorado has worked on several of the outcomes in Goal 3. 3.2 is the biggest one through self-directed vouchers, and grants are focused on reaching rural and frontier communities. Colorado is also working on Outcome 3.10 as they support kinship and foster families. They are addressing elements on 3.3 through stress management classes for caregivers. They would also like to explore making counseling and mental health services available through their respite vouchers.

- Idaho: Self-directed respite has been a powerful move in enabling families to find respite that works for them, especially in rural areas. They have also been working on culturally responsive supports such as bilingual care navigators and emphasis on increasing outreach with the Latinx population. They are being intentional about understanding unique challenges within different cultures and communities, such as external help vs. care being provided within families.

Additionally, they are exploring how to support younger caregivers who are currently or planning to pursue higher education and the resources they may need. They are working on a survey to better understand the number of caregivers in this position. Idaho offers a free caregiver navigation support network and is working to make sure higher education entities know about it. Finding the right language to reach caregivers has been a challenge. Additionally, Idaho is working with the Office of Drug Policy and Behavioral Health Systems to better understand the unique needs and challenges kinship care families face (Outcome 3.10). They also want to partner with the Office of Corrections on this work.

- Resource: Healthy Kids Colorado has developed language that can be helpful in talking with kids about caregiving. Erin Myrent will share with ARCH for broad distribution.

- Illinois: The Illinois Respite Coalition is collecting information from family caregivers through an ongoing [Caregiver Statewide Survey](#) that is posted on their website. The purpose of the survey is to understand what type of respite services family caregivers need in order to keep their loved one in their home as long as possible.

Illinois participated in the ARCH, NASHP, and Respite Care Association pilot on respite training. They are in the early stages of establishing a lending library of tech tools for caregivers to borrow, including tablets, Alexa devices, and virtual reality goggles as a way to offer virtual respite and address social isolation of family caregivers and care recipients.

- Alabama: Alabama has a caregiver wellness initiative. They just received a private hospital grant to expand mental health stipends for more families in one county. They hope to use these funds to leverage additional funds from the state mental health agency. They also shared about the interest in robotic pets to reduce isolation, especially for older adults.

- Washington: Using state caregiver funds, Washington has also utilized robotic pets and had mixed success with different populations. They have also used [Trualta](#) for any family caregiver who is interested in quick online training for things like how to safely lift and other safety skills.

WA Cares Fund, the state's long-term care insurance trust fund, has started to deduct funding from working Washingtonians to implement long-term care benefits for WA residents. The Lifespan Respite grantee has proposed in their most recent grant proposal to partner with decision makers about the long-term plans for that effort, especially how it will support family caregivers and how they can best work with family caregivers to help them use their benefits most effectively.

They are also continuing their outreach to and partnership with Tribes and want to grow them. This includes efforts to increase training of respite providers within Tribes to help providers meet state training requirements to provide respite, including a new virtual model. The hope is that these efforts can be replicated and adapted in other tribal communities. One potential challenge of this is geographic distance for in person training as well as limited Internet access for virtual training.

- Wisconsin: Wisconsin is looking at strategies to increase the number of respite providers, both providers establishing their careers and other individuals who need more training and support getting onboarded and qualified. This includes a pilot where they will offer stipends to incentivize non-professional caregivers like family and friends. They are also looking at lessons learned from related workforce initiatives done in the state, such as an effort to increase the number of providers in skilled nursing facilities.

Additionally, they are continuing their efforts to reach employers to support working caregivers. They recently built a relationship with the state's [Society for Human Resource Management](#) (SHRM) chapter to present at a conference. Nationally, SHRM has increased its footprint within support for working caregivers. [Find a local chapter of SHRM](#) .

- New Mexico: New Mexico started their first grant in 2022. They are starting several initiatives, as well as weaving existing efforts in the state into the grant. This includes training with partners about the work they will be doing through the grant, including with ADRCs and Single Entry Points. They are building a respite registry, as well as offering self-paced online training opportunities for caregivers. They will begin providing respite services in the

upcoming grant years. New Mexico has started engagement efforts with local Tribes, Pueblos and Nations to better understand their multiple and diverse caregiving needs and challenges.

■ **Barriers Experienced:**

- Public awareness of available resources and supports for family caregivers
- Language - reaching caregivers who may not self-identify, using culturally responsive language, etc.
- Workforce gaps - number of providers available, adequate training

■ **Opportunities and Want to Learn More:**

- States would like to learn more and explore Outcome 3.6: Volunteers of all ages and abilities are trained, vetted, and ready to assist family caregivers.
- State partner works with high schools and health care students to offer credit opportunities for students interested in volunteering for respite.
- Successful marketing campaigns to let family caregivers know about available services.

● **Next Meeting**

- Next meeting: July 13, 2023 from 2:00-3:30 pm (invite coming soon)

● **Contact Information**

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