

## CHAT TRANSCRIPT

### **Lifespan Respite Learning Collaborative on Implementing the National Strategy to Support Family Caregivers**

*September 5, 2024*

00:39:33 Barb Koumjian, LRW/PAVE: Hi everyone from Lifespan Respite WA!

00:40:14 Lisa Schneider: Hi!! Lisa Schneider, Executive Director with Respite Care Association of Wisconsin

00:40:16 Vivaldi, Kim: Hello from the Commonwealth of Virginia, Kim Vivaldi with Dars

00:40:22 Rebecca Hyde: Rebecca Hyde, New York State Caregiving and Respite Coalition -- unfortunately, I can stay for just 45 minutes today

00:40:23 Judith.Gaudet.CTR: Judith Gaudet, Policy and Program Development at RI Office of Healthy Aging

00:40:31 rosaly.n.alber@dshs.wa.gov: Rosalyn Alber from Lifespan Respite, Washington State

00:40:35 Susan Summers: Susan Summers, ARCH Respite (coming to you from Seattle)

00:41:09 Dr. Nelly Clotter-Woods: Dr. Nelly Clotter-Woods, Arizona Caregiver Coalition, azcaregiver.org

00:41:33 rdiawara: Good Afternoon, Roxanne Diawara AL Department of Senior Services, CARES State Director

00:41:48 Caitlin Gurney (NYS Office for the Aging): Caitlin Gurney, New York State Office for the Aging. I'll have to drop off around 3:30

00:41:58 AR--Naomi Toller, MS, RDN, LD, TTS: Hi everyone. I'm Naomi Toller. I am with Arkansas and I assist Sarah Schmidt with the Arkansas respite program. We are housed within DHS here in Arkansas.

00:42:07 Leslie's iPhone: Hi! Leslie, Respite Care Association of Wisconsin!

00:42:08 Adrienne Smith: Hi everyone, I'm Adrienne Smith of NM Caregivers Coalition.

00:42:18 Dana.allard-webb@dshs.wa.gov Washington state: Dana Allard-Webb, Washington Lifespan Respite Voucher Program

00:43:38 Illinois Respite: Tina Yurik, Illinois Respite Coalition

00:43:52 Donnie Lewis - Oklahoma Human Services: Donnie Lewis, Oklahoma Human Services

00:43:54 Lynn Gall, DHS: Greetings - Lynn Gall, Wisconsin Department of Health Services

00:44:20 Angela Rodriguez: Angela Rodriguez, South Carolina Respite Coalition

00:46:35 Judith.Gaudet.CTR: I am coming in at the 11th hour. Will this slide deck and any previous be any where that I am able to go back to for review?

00:49:33 Cheryl Dinnell: Meeting Notes and Presentation Slides and Discussion Group video will be posted in coming days

00:49:59 Jill Kagan:

### **National Lifespan Respite Conference Call for Presentations**

<https://archrespite.org/2025-national-lifespan-respite-conference/2025-call-for-presentations>

## **Innovative and Exemplary Respite Services**

Read more and application portal at <https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/>

Information Session Recording at <https://archrespite.org/library/information-session-for-2025-innovative-and-exemplary-respite-services-application/>

## **Respite Research Summit**

Website: <https://archrespite.org/news-events/2024-resepite-research-summit/>

Register:

<https://friendsnrc.zoom.us/meeting/register/tZYvduqtrDkoG9bnDiFSFhzLwWLZXiHSQi8#/registration>

00:50:25 Dr. Nelly Clotter-Woods: Yeah, Lita Nelson!!!

00:50:33 Jill Kagan:

## **Today's PPT Slides**

<https://archrespite.org/wp-content/uploads/2024/09/09-05-2024-National-Strategy-Learning-Collaborative-Slide-Deck.pdf>

00:53:50 Jill Kagan: @Judith.Gaudet.CTR All past meeting recordings and resources from this Learning Collaborative can be found at <https://archrespite.org/ta-center-for-respite/learning-collaboratives/#LCAdvancedTabs-5>

00:54:54 Cristina Amedeo - United Way of Rhode Island: Hello Everyone, Cristina Amedeo, Family Caregivers Alliance, Providence Rhode Island

00:55:12 Denise Meza she/they: Reacted to "@Judith.Gaudet.CTR ..." with ❤️

00:55:18 Dr. Nelly Clotter-Woods: Reacted to "@Judith.Gaudet.CTR ..." with ❤️

01:01:04 Barb Koumjian, Lifespan Respite WA: RE: the poll--there's more than a bit of overlap between choices 1 and 2 :)

01:02:14 Jill Kagan:

**Discussion Guide**

<https://archrespite.org/wp-content/uploads/2024/09/DISCUSSION-GUIDE-9-5-2024.pdf>


01:02:41 Lisa Schneider, RCAW: I think it's hard for Coalitions like RCAW (who are not the Lifespan grant applicants) to know exactly where the States are at, just know what we are doing at organizational level. My two cents :)

01:03:10 Lisa Schneider, RCAW: Replying to "I think it's hard for..."  
Anyone else feel this way??

01:32:12 Cristina Amedeo - United Way of Rhode Island: Silos, having to compete for funding with community partners, buy in from partners, reaching caregivers not associated with community agencies.

01:32:45 Tracy, LRW WA (she/her): Unpaid caregivers have overflowing plates and national funding so that when they move they can access paid breaks.

01:32:47 Judith.Gaudet.CTR: Reacted to "Unpaid caregivers ha..." with 

01:33:06 Judith.Gaudet.CTR: Reacted to "Silos, having to com..." with 

01:33:06 rosaly.n.alber@dshs.wa.gov: Finding resources/providers for isolated locations.

01:33:08 Illinois Respite: one sided partnerships

01:33:24 Lynn Gall, DHS: Getting people who are dealing with so many issues to focus on only the National Strategy. The strategy is so large and contains so much/many recommendations, that asking for more than one thing at a time, or educating about more than one component at a time, becomes challenging.

- 01:33:36 Denise Meza she/they: culturally and diverse messaging/outreach tools to reach underserved communities
- 01:33:57 Tracy, LRW WA (she/her): Reacted to "culturally and diver..." with 👍
- 01:34:11 Lynn Gall, DHS: An additional person at the state level to work on implementing the National Strategy would be GREAT!!
- 01:34:14 Lisa Schneider, RCAW: 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.
- 01:34:21 Barb Koumjian, Lifespan Respite WA: Helping potential partners realize the value of a broad, state-wide coalition for policy change/creation
- 01:34:24 Toy Pilot: Reacted to "Finding resources/pr..." with 👍
- 01:34:36 Lisa Schneider, RCAW: Reacted to "An additional person..." with 👍
- 01:34:54 Toy Pilot: Reacted to "Unpaid caregivers ha..." with 👍
- 01:34:58 Judith.Gaudet.CTR: Though new to this, I would say increased advocacy for use and reimbursement for CHW's who can make connections in hard to reach populations that are culturally and linguistically appropriate.
- 01:35:17 Jill Kagan: Reacted to "Though new to this, ..." with ❤️
- 01:35:33 Denise Meza she/they: 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
- 01:35:35 Barb Koumjian, Lifespan Respite WA: Reacted to "culturally and diver..." with 👍

01:36:01 Barb Koumjian, Lifespan Respite WA: and federal line-item funding for respite care, family caregivers are part of the health system.

01:36:35 Tracy, LRW WA (she/her): 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.

01:36:37 Cristina Amedeo - United Way of Rhode Island: Reacted to "a public health camp..." with ❤️

01:36:46 Cristina Amedeo - United Way of Rhode Island: Reacted to "and federal line-ite..." with ❤️

01:36:52 Cristina Amedeo - United Way of Rhode Island: Reacted to "A national marketing..." with ❤️

01:36:54 Judith.Gaudet.CTR: Replying to "a public health camp..."  
Hello Denise, nice to "hear" from you!

01:37:13 Tracy, LRW WA (she/her): Reacted to "and federal line-ite..." with ❤️

01:37:16 Denise Meza she/they: Replying to "a public health camp..."  
Hi Judy! so nice to be in the work with you again :)

01:37:21 Cristina Amedeo - United Way of Rhode Island: Replying to "a public health camp..."  
3 of us here, this is so exciting!

01:37:28 Lisa Schneider, RCAW: Reacted to "and federal line-ite..." with ❤️

01:37:30 Judith.Gaudet.CTR: Reacted to "3 of us here, this i..." with 👍

01:37:31 Barb Koumjian, Lifespan Respite WA: For the next iteration of the Strategy---for State-level suggestions, bring together action items for private/community sector and state-agency-level actions.

01:37:32 Lynn Gall, DHS: 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.

01:37:35 Dana.allard-webb@dshs.wa.gov Washington state: Not all cultures are ready to trust Lifespan respite outsider respite providers.

01:37:44 Cristina Amedeo - United Way of Rhode Island: Reacted to "Not all cultures are..." with ❤️

01:37:54 Dana.allard-webb@dshs.wa.gov Washington state: I need to go to another meeting. Thanks for this great meeting.

01:38:11 Tracy, LRW WA (she/her): Reacted to "Not all cultures are..." with ❤️

01:38:15 Barb Koumjian, Lifespan Respite WA: Re: National awareness campaign--isn't there a TA Center funded through ACL that's supposed to be working on that?

01:38:36 AR--Naomi Toller, MS, RDN, LD, TTS: I have to head to another meeting. See you all next time!

01:38:38 Cristina Amedeo - United Way of Rhode Island: So true Dana, I spent half of the morning talking about this subject at a Black & Aging Resource fair

01:39:08 Lisa Schneider, RCAW: Reacted to "Not all cultures are..." with ❤️

01:39:33 Lisa Schneider, RCAW: Reacted to "For the next iterati..." with 👍

01:40:25 Denise Meza she/they: Reacted to "Re: National awarene..." with ❤️

01:41:10 Illinois Respite: continue to expand state agency networking oppt

01:41:20 Lisa Schneider, RCAW: Reacted to "continue to expand s..." with 👍

01:44:56 Judith.Gaudet.CTR: Do most states have Community Advisory Boards?

01:46:03 Judith.Gaudet.CTR: CABs are also known as public reference groups or stakeholder ask forces.

01:48:20 Jill Kagan: What about direct care workforce and building respite provider/program capacity?

01:48:41 Tracy, LRW WA (she/her): Replying to "Do most states have ..."  
For Lifespan Respite WA <https://www.lifespanrespitewa.org/> we call it a coalition.  
Unpaid caregivers and professionals. <https://www.lifespanrespitewa.org/lifespan-respite-coalition/>

01:48:42 Lisa Schneider, RCAW: Reacted to "What about direct ca..." with 👍

01:50:02 Lisa Schneider, RCAW: Bringing Respite to Your Community

01:51:13 Lisa Schneider, RCAW: More focus on helping to develop respite programs in areas where it is needed.

01:52:26 Illinois Respite: Reacted to "More focus on helpin..." with 👍


01:55:02 Tracy, LRW WA (she/her): 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 4 options of up to 2-4 nights with each other and their loved ones.

01:56:07 roselyn.alber@dshs.wa.gov: The State of Washington Requires specific training to be an IP Respite Provider.

01:58:14 Judith.Gaudet.CTR: Additionally, in most states the wait list for approval for employing family caregivers is 2 years or more.

01:58:16 Lisa Schneider, RCAW: TOTALLY AGREE!!! SPOT ON!



- 02:01:17 Tracy, LRW WA (she/her): Thank you! Very beneficial and look forward to all the notes from the break out rooms and the upcoming summit!
- 02:01:29 Lisa Schneider, RCAW: Thank you!!
- 02:01:36 rdiawara: Thank you!
- 02:01:41 Barb Koumjian, Lifespan Respite WA: Many Thanks everyone! It's been great.
- 02:01:42 Illinois Respite: Thank you!!!!
- 02:01:45 rosalyne.alber@dshs.wa.gov: Thank you!
- 02:01:48 Susan Summers: These discussions were thought provoking. I loved hearing your insights and about your experiences. Thanks!
- 02:01:58 Tracy, LRW WA (she/her): Reacted to "These discussions we..." with 
- 02:02:05 Kate Rasulova, DSAAPD: *Thank you so much for all your efforts and time!*