



Nevada Lifespan Respite Care Coalition
Community for Respite Meeting

October 6, 2022

Time: 9:00 a.m.- 10:00 a.m.

Microsoft Teams meeting

Join on your computer, mobile app or room device

[Click here to join the meeting](#)

Meeting ID: 249 620 217 178

Passcode: hvPZQZ

Or call in (audio only)

[+1 775-321-6111,,323714463#](tel:+17753216111323714463) United States, Reno

Phone Conference ID: 323 714 463#

Thank you for planning to attend this Teams meeting.

Vision:

Adequate Respite Care for All

Mission:

The mission of the Nevada Lifespan Respite Care Coalition is to support caregivers in our community by promoting awareness and access to, as well as coordination and advocacy for, respite services in Nevada throughout the lifespan.

Attendees: Cheryl Dinnell, David Nichols, Cory Lutz, Annemarie Culp, Cathy Povich, Yazmin Orozco, Josie Clymens, Ashley Martin, Justin Hansen, Deidre Manley, Tori Diego, Barbara Lewison, Allie Blum, Kathy Doyle.

9-9:15 a.m.

1) Introductions and Check-In:

- ***Pet Peeves? What is one of yours?***
- Cathy Povich – Someone in the office uses the last form without making new copies.
- Yazmin – Dog makes chewy sound when licking his paws.
- Cory – Toilet paper is not over, because over is the correct way.
- Annemarie – Super hard to clear out email inbox, and it gets filled again
- Josie Clymens – Can hear people chewing and sloshing food around in their mouth.
- Ashley – People driving slowly in the fast lane.
- Justin – Someone finishes something and leaves it in the fridge or counter – Just throw it in the trash!
- Deidre – Young adult daughters facetime at any time, even night, and she has people with her! Can't just pop into my bedroom or living room without notice!
- Tori Diego – People who are slow driving in the fast lane.
- Barbara Lewison – People who refuse to look you in the eye when passing. Afraid to say hi. Miss the small town of 1950 when people greeted each other.
- Allie – When dirty clothes are left right next to the laundry basket.
- Cheryl – Don't like it when people mischaracterize others down to a single flaw and misjudge them based on their least admirable trait.

The RAISE Act Policy Roadmap www.nashp.org/roadmap-for-family-caregivers/ has been presented for public comment for 60 days. It can be found at [RAISE Act State Policy Roadmap for Family Caregivers - The National Academy for State Health Policy \(nashp.org\)](https://www.nashp.org/roadmap-for-family-caregivers/). The link for comments is [2022 National Strategy to Support Family Caregivers | ACL Administration for Community Living acl.gov/CaregiverStrategy/Comments](https://www.acl.gov/CaregiverStrategy/Comments).

9:15-9:45 a.m.

2) Challenging Questions/Discussion – To better understand the needs of family caregivers, data that illustrates caregiver support needs and potential service gaps needs to be collected. This data can be used to target resources to caregiver supports and services that help family caregivers continue to provide care at home. Getting actionable information from caregivers requires asking the right questions. What queries have the most practical value? “Actionable” means we can do something about it! Share your experience developing actionable steps from data collected.

3) Caregiving Context:

- Define caregiving in broadest language: During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability? Did you do something for them that they cannot do for themselves? – Would this get caregivers who don’t identify as caregivers? Would it pick up too many respondents inappropriately?

David – I believe those are good questions but might need to be edited. I don’t have a screening tool because I am talking to the caregiver directly and ask them if they help with connecting to resources or scheduling appointments. Those questions allow me to tell them that they are seen as a caregiver. They assume that they must be in the home 24/hours. I deal with a lot of out of state caregivers but if they weren’t there to help, things would not be handled. So, I ask if they help with coordination.

Allie – I think that starting broad is especially helpful for those who don’t identify as caregivers but should be followed up with questions to identify tasks that they perform. If that’s too many questions, maybe follow up questionnaire to reassess what caregiving they are involved in.

Cory – I agree with David and Allie about broad question and narrow it down. Those who call me already know that they are caregivers. Do you take care of, what do you do for, and other questions to identify and come to realization that they are caregivers. Lead them in a direction to accept that they are caregivers and need respite. Ethnic reasons/socio dynamic behind.

Barbara – Respite application has questions answered as None/Supervised/Hands On in types of care with ADLs. Also have box on the physician statement to indicate that the live-in caregiver is actually necessary for the ADL.

Annemarie – Draw a careful line between caregiver and anyone who provides care. Normal task/routines don’t qualify but ask questions about supervision and medical needs, and anyone who needs assistance but would not be able to get it by themselves. Are these routine things.

Allie – To piggyback off Annemarie – maybe ask something like age-appropriate, developmentally appropriate tasks that one would expect of a child. Super important to fit in culturally competency; there are a lot of cultures where care is expected of them. Intergenerational care.

Josie – Question about a client with stroke that affects physical and mental health, but wife takes care of the medical needs and doctors’ appointments. Count them as a caregiver. Follow-through on the medical treatment; family caregivers are crucial link between medical providers and treatment plan compliance. But maybe some would not consider a person a caregiver without hands on care?

- What is most valuable to know? Relationships, length of time providing care, how many hours of care, main health problem of care recipient, which personal care/household tasks performed? Any actionable items from these questions? Do these just describe caregiving?

4) Demographics: Age of caregiver/care recipient, race/ethnicity, sex/gender, geography, socio-economic status, income level, diversity? Any actionable items from these questions? Will these lead to true demand/service gaps for caregiver supports? Or just lead to trying to increase diversity reach?

David – Most of the demographics will help, especially age because that will tell what services they are eligible for. A gap might be found if services are needed for certain age group. Age of care recipient and age of caregiver.

Cory – Agree with David on demographics, even broader. Do they qualify for services based on income-level, such as food pantry, transportation? Are they a working-class caregiver? Help employers understand how to help them? How many are leaving jobs to become unpaid caregivers? Some of the demographic

questions we ask because the state asks us for it, maybe also for referral purposes. Referrals help caregivers.

Deidre – Cory said the same things I would say.

Justin – When you ask all these questions, people want to know what’s going on. Discouraged, going other places than what they wanted. Causing problems for them. Classes of races, cops after me, and know that I feel that’s asked and why would I tell them that? Explain why when you ask. Is it appropriate to offer an “opt-out” no response on certain questions?

David – Do understand that. Average individual would prefer not to disclose their race or income. African American would fear they are typecasted or if services are different or if they will be contributing to a false narrative. That’s a right for everyone to not reply. What value will come with being truthful if I respond? Important information to have when planning for the future and looking at disparities.

Annemarie – Hearing this, it comes up in conversations regarding citizenship, underserved populations. If we could get the basic data that we absolutely need to perform our services and another section where we clearly explain that this is strictly for advocacy/planning purposes. Frame it that way.

Barbara – Our application asks for the information the state asks for, as far as income/race/etc. The state is driving what we ask for.

Cory – The state has specific things for data capture for all grantee programs. We can ask questions beyond but there some that are strictly asked for.

Barbara – What about the caregiver who is putting their health at risk? They are considered the caregiver, but they really need is a caregiver as well. Maybe leading questions to get to all care needs. I do make it clear that the income info is not used as a basis for approval just for statistical purposes. Service Gaps I run across... An older couple out in the rural areas that have not family or friends and there are no agencies in their area, or they cannot afford an agency.

- 5) Questions of Needs: stress reduction, family dynamics, working caregiver, financial burden, behaviors and mental health, legal issues. Interventions: training/classes, help accessing services, support groups, counseling to cope, respite care. What are the best questions to ask?

Cheryl – In looking at caregiver assessment, there are questions so that working caregivers could be identified. There are also questions, a series of questions, that ask about ADLs/IADLs and if this is a care recipient need, if the caregiver provides it, and if so, does the caregiver need any training or assistance to perform this task. Asking lots of questions raises concerns that it will overwhelm caregiver and that some questions might be difficult to answer. It’s hard to capture every single task a caregiver provides, but where there is need for training and assistance. Since families are assumed to take on any task related to care management at home, can caregivers say Yes/No to the various tasks they’ve now been assigned to complete or make happen? Is it fair to say that I don’t feel comfortable.

Having some questions about the caregiving situation since it can be really hard. Having questions about some of the impacts of care.

Justin – It does relate a lot of good information back if they answer honestly. Do like staying to the point. Would help.

Allie – I agree with Justin. Wonder if there’s a way, based on this answer, categorize questions. Look at question 37 for three kids. Need to schedule it on my calendar to do that. If there’s a lot of questions that’s a non-starter for me; a few questions with follow-ups, much more doable. That’s why picking the most valuable questions so that we aren’t asking a lot of questions, intrusive; ones that will pay off on for all our caregivers across the lifespan.

- 6) Outcomes: Improvements in confidence, mental health, physical health, coping with care demands. Mostly need a Pre- and a Post-Survey to assess change. How much are you struggling? What outcomes did the intervention achieve? What has been missing from life & how to get it back? Respite outcomes: Freedom, Support, Connections.

Justin – The only thing on an outcome is to follow up on an outcome; following up to see if it created positive outcomes. Not just “we delivered the services; you’re good.”

Tori – We do our evaluation and a pre- and post-survey 6 weeks apart to see if our program is making a difference. We've added the pathways club at the tail end of our workshop; leave the door open for those interested in getting referrals/more services, housing, transportation etc. Still connected to us and keeping in touch that way.

Annemarie – I think we need to look at the mental health aspects; huge shift in depression/suicide, overall wellbeing and how they feel about their mental health. We need to give good caregiving services but also connect to good mental health support. Tailor questions to learn that about them. Caregivers burden and how it's reflecting on their own mental health.

David – I agree with Annemarie. When I think of respite, I think of stress reduction/relief that plays into the mental health component. More feeling of connectedness to the community, which also helps with mental health, and optimism in getting the help/connected to resources.

Josie - For mental health services it might be beneficial to share the CARE Team (adult crisis mental health team) with your clients 877-283-2437

9:45-10:00 a.m.

7) NLRCC Board Update

- Next Board Meeting November 7th, 2022, 9am – 3pm, agenda and meeting link [Home \(nv.gov\)](https://www.nv.gov)
- Next Community for Respite Meeting is Friday, November 18th from 9am-10am, agenda TBD.

8) Group Updates:

- Caregiver Recognition Event [17th Annual Caregiver Recognition Event](#)
- Please check out our upcoming Seniors in Service Fundraiser site... Put your bowling teams together and come out for a fun day... <https://www.bowlathon.net/event/pirates-pins-and-pints-2022/>

Thank you for coming!

Guiding Principles and Agreements

What conditions must be met for you to fully participate?

For individual participation:

- Everyone has a voice.
- Everyone is encouraged to participate.
- Stay on topic or focus.
- Identify yourself as we communicate during virtual and telephone meetings.
- All questions are legitimate—there is no such thing as a stupid question.
- Trust and a safe space are critical to our ability to take risks.
- Everything that is shared in the room stays in the room.
- Listen for understanding: encourage perspective-taking—even if we don't agree, we need to listen and learn from others' experiences.

Overall considerations:



- Honor individual time constraints and limitations based on their organizational affiliations and commitments.
- Maintain a structure that is self-organizing and regulating—insure, in addition to the facilitation, there is a chair to manage NLRCC meetings.