



Nevada Lifespan Respite Care Coalition
Community for Respite Meeting

May 19, 2022

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

Microsoft Teams meeting

Join on your computer or mobile app

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[+1 775-321-6111,,277429214#](#) United States, Reno

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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.

Attendance: Cheryl Dinnell, Yazmin Orozco, Cory Lutz, Tori Diego, Charae Wamsley-Gipson, David Nichols, Sharifa Wahab, Barbara Westcott, Dawn Newburg, Elizabeth Macias Romo

1) Introductions and Check-In:

Who was your role model when you were a kid and why?

- Cheryl – Admired her dad, who carefully considered things, had long discussions with her when she did anything wrong.
- Cory – Parents were hardworking, instilled work ethic, encouraged fun, friends, sports.
- Dawn – Grandfather was someone, other than parents, to go talk to. Taught her nothing is as bad as it seems.
- Tori – Both parents from Guam, had challenges I didn't know about until I was an adult.
- Charae – Grew up in Canada as a tomboy, so hockey players like Wayne Gretzky were admired.
- David – Liked dads on Family Matters and Roc who gave good counsel to their families.

2) Challenging Questions/Discussion – The care from family caregivers truly constitutes a cornerstone of the healthcare system so maintaining family caregiver well-being is therefore of paramount importance. Although respite interventions are generally considered an effective support system, these tend to be underutilized. It is therefore important to identify the factors that promote or impede the use of respite services.

Since family caregivers are not likely to know about respite or self-identify as caregivers, let's explore who they would talk to about their care support needs, beyond their family and friends.

- Charae – Considering when and where would it have been most helpful to learn about respite, we should ask the caregivers. Include that on an evaluation. It's those support networks like friends and family with whom it is easier to open up with and share. Maybe it's a faith based setting or day-to-day network but that would be harder for us to tap into.
- Cheryl - Are we utilizing caregivers we already know in reaching out to other caregivers, create some messaging around that because they are those who have that lived experience, they are the ones who could plant that bug in a caregiver's ear about self-care and not be looked at as a professional who is

evaluating them for how well they are holding together?

- Cory – HHOVV referrals are word-of-mouth (from friends) but 90% come from social workers (such as hospice). Another surprising source of referrals is doctors' offices, but we may have board representation from certain medical offices that are actively promoting HHOVV. HHOVV also makes referrals to other resources as well - to make sure caregivers have as many resources as possible. We do ask if clients were given any resources and if they used them.
- Dawn – At ALS we try to be a trusted source. At initial diagnosis, people are so overwhelmed they can't remember much of what they were told. It's important for social workers/case managers to keep an open dialogue with caregivers. Sometimes it takes a while before they are ready to have a respite discussion.
- Cheryl – The focus on diagnosis and learning what they needed to do as a caregiver initially puts their own needs on back burner. Were they open to discussion when pressures/burden of care finally was having an impact on them? What triggers their willingness to have a respite?
- Dawn - Caregivers don't recognize themselves as caregivers. The term Respite has a different connotation. Realization that "I really need a break" and how to do that without changing the dynamic of what is set up is part of a learning process.
- Cheryl – Is there anything being successfully used for communicating that? Saw a nice article on the new NevadaCaregivers.org website but they still need to get people to the website to see it. What is going through their minds when we talk to them about respite and respite funding?
- Dawn – Sometimes I think they are surprised when they finally get it - "You mean, for me?" Does everyone understand what respite is?
- David – Connotation of respite does require a bit more education. When caregivers are asking for respite, they are looking for more PCA-related support. When I mention the respite programs, the caregivers ask "Are they able to bath? Are they able to help dress?" a lot of the time. The programs we have do not engage in personal care type things. They are stringent related to the various services: homemaker, respite, personal care. The negative connotation of respite comes with "For yourself." When calls come in, caregivers are burnt out for sure, but mostly because their loved one is not receiving the services that they are eligible for. They don't fill comfortable getting a service for themselves when their loved one is not getting all the services they deserve. Providers are big on the terms and what that service can provide. They get paid different rates for different services. Caregivers do want respite, but they don't want to admit it. It takes about 3 months-6 months of talking to them about respite to finally accepting it. But that's not the end. Getting the resources/scheduling in place takes time. Resource is not available; there's time limits; distance is a barrier.
- Tori – Regarding the education on respite – when caregivers join our Powerful Tools for Caregivers class, they learn about respite but will comment "Oh, I don't need that. I can do it." We know that they can provide care, but it is also nice to have a break for themselves. "We are not trying to take anything away from you, but we are trying to help you continue to provide care." Regarding where we can connect with caregivers is through providers and community partners. Referrals from rehab or getting into places where they are going with their loved one anyway, maybe they will see a brochure, a poster, and it will introduce them to the concept.
- Cheryl – Some states have run awareness campaigns to identified referral sources, such as doctors' offices, to spread the word. But even when caregivers are ready for respite, at a point where they really need it, we give them more process to go through. Application, identify provider, schedule intake/evaluation, look at scheduling, etc. all stretch out the time it takes to get a caregiver to respite. It is not a quick turnaround. Speeding the process up would be a wonderful outcome to work toward. Caregiver in Powerful Tools classes want to become better caregivers, and they might be coming in thinking "this is the fix" – that they will become better at caregiving and the burdens will lessen or go away.
- Tori – A lot of caregivers come in, saying "I've been a caregiver for years. I don't know what you can teach me." Or they are new caregivers and want to be better caregivers. We tell them that we will talk about self-care and building a team around their loved one, so this training is more for them than for their loved one. Ultimately, 90% of them are burnt out and looking for how to become better caregivers.
- Cory – Caregivers in the course were looking for better ways to cope - to be a better caregiver and find

resources that will help.

- Cheryl – Knowing that caregivers are coming to us on a journey, a path, of giving care and maybe starting to recognize their own needs, what messaging would we want to say to them, to get them to at least allow being assessed for their own needs. What does respite need to look like for me? What signs along the road would we need to put out there, maybe building on one message after another?
- Dawn – It's almost like putting your own oxygen mask on before helping others. That's basically the message we need to give them. You need to be sure you can do what you need to do.
- David – I sell respite by encouraging them to think about what they could do with that time, what they could look forward to doing. Make a goal of planning for yourself – to go out for a walk, get nails done, to do something for yourself. You must plan to make that happen. If you don't have a connection with respite resources, that will never happen. This helps them consider stepping away from the caregiver role and allows them to be open to respite – a different way for them to think of respite.
- Cheryl – Since COVID, would planning for an emergency make more sense now? When they had to do and cover everything, and had little support, would that make respite seem wise to pursue? The planning needs to happen now, instead of reacting. You may never plan to place your loved one in a nursing home, but you are providing nursing level supports at home. What if you were not able to provide care for some reason, would you not want to know that a nursing home could provide care for a period of respite? Wouldn't you want to get that set up now? Get that paperwork/process piece out of the way. COVID had several silver-linings when consultations could be handled online/virtually. That has removed some challenges off their plate, but they still must be there! Do other services – homemaker, PCA services, chore, etc.- fulfill a respite role and provide a respite break? Or does the caregiver still have to be there or are other services of such a short duration of time that the caregiver can't benefit from it?
- Sharifa – COVID was hard, a lot of people don't know about respite, need to educate them. "What a lifesaver, I want this!" PCA services do allow caregivers to go out during that time. Caregivers have their own doctor's appointment. Socialize, do lab work, whatever. 70% don't know about these services.
- Cheryl – We might need to think about the scheduling of PCA services so that they could also fill a respite need.
- David – At times it can be difficult to connect with services, so we do try to blend those services so that respite can be achieved. PCA has a wider range of what they can do. Some respite programs cannot even touch the care recipient. Socialization for care recipients is also important – they would benefit from the respite as well. Looking at respite as someone else to talk to or to help them organize. You must look at all three: Respite, homemaker, PCA services – and blend them to get that holistic experience that caregivers need. That's what caregivers are really wanting. Provider by provider, these distinctions are different. Makes it hard to blend them together.
- Cory – If caregivers are nervous to leave a provider in the home, I tell them "You don't have to leave your house. Have that peace of mind that you can be there, uninterrupted, while someone else is providing care." Anything that can help them is a break too - helping with dishes, bathing - each is one less thing for the caregiver to do.
- Cheryl – These stories and examples of blended services are what caregivers need to hear. Maybe it's hard to visualize, or maybe coming from a professional, this message doesn't come through.

3) NLRCC Board Update

- Next NLRCC Board Meeting June 21st, 10am-12noon, agenda and meeting link [Home \(nv.gov\)](https://www.nv.gov)
- Next NLRCC Community for Respite Meeting, July 15th, 9am-10am.

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.