



Nevada Lifespan Respite Care Coalition
Community for Respite Meeting

July 15, 2022

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

Microsoft Teams meeting

Join on your computer or mobile app

[Click here to join the meeting](#)

Or call in (audio only)

[+1 775-321-6111,,639544229#](tel:+17753216111639544229) United States, Reno

Phone Conference ID: 639 544 229#

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, Michelle Gonzalez, Jodi Collins, Barry Gold, Sonia Ruiz, Jeff Dold, Terri Schlegel, Shelli O'Donnell, Riley Franco, Kathy Doyle

1) Introductions and Check-In: *What's your nickname and who calls you that?*

- Cheryl – Mouse-shoes by parents and Sweetheart by husband
- Jeff – No nicknames, "Just Jeff"
- Charae – In hometown, family nickname is Walmer - even on license plate. Passed down to me.
- Cory – "Cory Dawn" called by husband.
- David Nichols – Lot of times I'm called Nick or D. Nick, or David Aaron (my middle name). Snacktooth or Snacks by family after losing front two teeth.
- Barry Gold – Don't have nicknames I'm aware of.
- Jodi Collins – Husband calls me Sweetie, even people at his work don't know my real name.
- Michelle Gonzalez – Michelle, my Bell – Beatles song I was named after.
- Sonia Ruiz – No nicknames.
- Tori Diego – Tori is my nickname, short for Victoria. Dad calls me Victoria when I'm in trouble.
- Yazmin Orozco – Tough to pronounce my name, so shortened to Yaz.

9:15-9:45 a.m.

- 2) Challenging Questions/Discussion – A key issue raised by caregivers is frustration that it is difficult both to work and to qualify for governmental benefits, placing caregivers and the people they care for in financial peril – both in the short- and long-term – particularly given the added financial burden associated with certain care needs. How can we help them bridge that gap?
- Where care recipients have access to LTSS supportive services, are such services compatible with full-time employment of caregivers? Are these services readily available and affordable?
 - Cheryl – We need to assess the financial impact of caregiving to give credit/allowance to qualify for benefits. Families might have expended a great deal of money to accommodate a care recipient at home, but they receive no supports in exchange.
 - Barry – AARP caregivers on average spend 25% of income taking care of other people. We don't have state income tax credits as some state do. AARP is pushing for federal tax credits for family caregivers as a goal. In applying for and becoming eligible for services, understand not to co-mingle your money.

Question is how to give them information before they've done that. People get divorced – who would recommend that to someone?

- Riley – Some social workers might know more but she heard about an option for a “financial divorce” rather than legal divorce, to create a financial separation for Medicaid eligibility.
- David – Medicaid Trust takes planning 5-7 years in advance of applying for Medicaid assistance. When people need it, it's past time to use strategy. Need platform for educating families about it, following up with families, and planting these messages. Free legal services would help with these questions.
- Cheryl - We hear about tax credits, but we already have a federal dependent care credit - so how do we differentiate the cost of dependent care and need for additional caregiver tax credits? At discharge from hospital, do working family caregivers say, “Yes, I can work and provide care too.” Or decide to relinquish employment and become an unpaid full-time caregiver?
- David – No real decision is made but it's like falling off a waterfall. Hospital will harass you. Say “No, I can't” and let the hospital figure it out, but most family caregivers figure they'll work it out from home. Not knowing their rights. I have caregivers who call to say they must work tomorrow and need someone to come in and provide care. This isn't really respite. In a lot of cases, people must quit work or take leave. Don't know any care providers who provide 8 hours of coverage every day.
- Cory/David – Hospital to Home does help with this transition. Senior Services program helps but even then respite is only 4-8 hours per week. They have been able to help people connect with adult day programs quickly. Still a lot of needs.
- Barry – State passed a bill regarding hospital to home program as well as discharge planning. Which employers have caregiver-friendly benefits? Most do not. AARP push caregiver Sick Leave Bill to use that paid time to help take time off for care, doctor appointments. 60% of caregivers are working full- or part-time. Caregivers find out that they do not have caregiver-friendly work benefits. When you have caregiver-friendly benefits, you have more productive employees.
- Cheryl – Even caregivers who work in HR departments can't find the benefits they need and must resign their positions. There is more virtual work than there has ever been before, but care still may make it difficult to do both.
- Riley - Complicated issue plus an immediate need to provide care – either you do, or you don't. The impact of leaving your job has great impact on caregivers – loss of benefits/income/identity wrapped up in it. Some work at federal level, but here locally, AARP has committed to target large employers for outreach to make them caregiver-friendly. Free resources available online. Supply information to help HR department or managers to be more caregiver-friendly. I also own a business and know it's an uphill battle. Focus of AARP during next several years. Gaining some interest from employers in Las Vegas at least.
- Barry – We are hopeful to gain more support for Sick Leave bill, as legislators pre-COVID were not supportive but now see how important it is. They had to take care of someone during COVID. Maybe something good will come out of this.
- Cheryl – Lots of requests during COVID about how to be paid caregivers, but options are slim. Look at greater possibility of job-sharing, part-time work. Not any government agency provides service coverage or will pay for 24/7 care needs, and few options to be hired as caregivers. 1) Hired by agency assigned to be care provider for loved one 2) allowed pay for skilled-by-unskilled programs if not legally responsible. Care recipient must typically be Medicaid eligible. Not universal acknowledgement that family caregivers are holding down a big piece of the LTSS system because of their generous giving of self. Trying to cover children/working spouse from a hospital room puts caregivers in a place of anxiously looking for a care recipient's release to go back home. Reality hits at home, as caregivers don't have a pre-conception of what that caregiving role entails. NLRCC has offered a recommendation for caregiver assessments to determine how prepared they are to continue care at home and what supports they need at home. Had some interest from legislators about that issue. Shouldn't be sent home from hospital until we've explored these issues.
- Jeff – Day programs do help support working caregivers. A dollar saved is 2-dollars earned. If you can just find services that are more affordable, then you don't have to earn the money, pay the taxes on it, spend it out. If affordable care is out there, that's the most valuable thing. People come to me are trying

to balance out their lives, whether it's kids, grandkids. Some of them are 4-generation homes trying to do it all. They come with all these questions, and most of the time when we're done discussing the options of adult daycare, they say "how come we didn't hear about this before? How come you're not out in the community letting people know there's another option?" They know two options: 1) go into a facility or 2) get in-home care. If it's a working caregiver, they drop off their loved one at our "club" and pick them up after work. And it can work out smoothly for about \$42/day if grants cover some of the costs. Private pay is \$85/day. People who have dementia are considered "not curable" - at risk of being institutionalized. Lots of opportunities for adult day programs to fill a need. We've served over 800 families in the 12 years of operations. Hear back that it was Godsend to have these services.

- Cheryl – Adult Day programs were designed to help working caregivers. How well is that information shared? Don't know at what point family caregivers start looking for those resources. COVID put a hamper in any congregate setting serving vulnerable populations. That may be lingering in people's minds. I don't see a whole lot of new openings. Day programs were under restrictions, are not now taking clients they previously served because COVID amplified their liability risk.
- Jeff – Salaries have doubled. Now we can't hire people at the \$9-12/hr – now closer to \$20/hr. Must work smart. Those who need 2-3 caregivers to help with bathroom assistance and feedings, it is not feasible to do that. There are some county-subsidized day programs like DayBreak that are still open and can do those levels of care because they have nurses on staff.
- Cheryl – In qualifying for benefits, walking away from your job may not bring your income low enough to qualify for benefits, when resources limits also apply. Fact that programs cannot cover all the care needs but we ask family caregivers to do all of them, with nothing else. Family caregivers without education, training, doing care with minimal instruction from nurses. Then it's left in their hands, and we trust family caregivers to do it. When it comes to helping caregivers, we have these restrictive options based on level of care and what a provider will and will not do. Why are we not combining resources and supports for the caregiver, even just for respite purposes, if they need nursing level care? Why are they not paired with a nursing facility for temporary care? I may not need the support all the time but I ought to know where I can get the right care.
- Charae – Since COVID has died down, more and more folks utilize long term care facilities for a respite stay, a week at a time. It's just something that, during the pandemic, no one was using. As these facilities are opening up again. Family caregivers have been so happy to use them for their loved one. But I have also been getting 4-5 people applying for respite for those who already live in a nursing community. Families are hiring/paying for health care agencies to provide supplemental support to the nursing facility (due to workforce shortages at the facility) so their loved one gets the attention they need. And applying for respite to pay for it. Unfortunately, this does not meet our requirements for respite.
- Cheryl – In thinking about caregivers, if employment is not going to be possible or the care available isn't sufficient that they would have to hire staff to supplement it, what LTSS package would be for a family caregiver, forced to be a caregiver because of the care demands? What would we want to make sure was included in that? If they've lost their income, we should give them something in exchange for that. I advocate for respite, but other ideas would be training and continuing education funds to continue to get schooling, get training to add to a resume so that they are working at a craft while they are providing care? Paid leave, employer insurance extensions, tax credits. What would we based that care package on – hours of care, skill level? Caregiver Support Package of services and supports – maybe even a nurse on call that they can reach out to, discounts for medications or equipment, offset healthcare costs, mental health counseling, anything they might be paying out-of-pocket.
- Barry – There is hope for the future. Alzheimer's Association made a recommendation - and AARP supported it - for a "structured caregiving program." Some states have instituted a waiver program that you can do or a couple of different models, that provides training, support, and in some places even pay for caregiver who normally can't be paid, like spouses. Chuck Duarte made the recommendation. Hopefully to get a piece of legislation in our next session. Encourage you to have Chuck come to talk about it. New wave sweeping the country. A different approach that does do some of the things mentioned.
- Cheryl – That gap is pretty wide for family caregivers who are not getting support, not qualifying for

support, and those who are. A doctor-order package of preventative healthcare (in recognition of healthcare impacts of providing that care long term) ought to go to that family caregiver. And explore ways that they can become paid family caregivers. That isn't the desire of every working caregiver, but if they are stepping away from another job to provide care, even some income might be very beneficial. The pay for providing care, including respite, is very low. Respite under Medicaid is only authorized for \$9.75/hr. In our wage increase environment and inflation, even agency employees are only getting \$12-15/hr. from providers who also require backgrounds, training to manage liability/risks that the employer incurs. If we could get providers to provide training to family caregivers at a minimum, it might also connect caregivers with co-workers at that agency who could provide respite when they needed support. There is a huge need for PCA services. Chuck Duarte has talked about it. We need to double the number of paid providers to meet future demand. Nevada is the number one state for aging population. The question is how we meet that demand. And what are we going to do for family caregivers who otherwise don't qualify for supports and services?

9:45-10:00 a.m.

3) NLRCC Board Update

- Next Board Meeting August 15, 2022, 10am-12noon, agenda and meeting link [Home \(nv.gov\)](https://www.nv.gov)
Next Community for Respite Meeting is Thursday, September 15th from 9am-10am, agenda TBD.

4) The email invite for this meeting was improperly used for other purposes. Please refrain from using the email list for correspondence or promotion. We will also take steps to prevent this misuse.

5) Group Updates:

- Riley – If anyone has caregivers who would benefit from more support from their employer, AARP would be glad to do some outreach to their employer, for training or information. Anyone across the lifespan.
- Charae – We just started new year and have funds for the Alzheimer's Association respite care grant. For caregivers living in the home with someone with dementia. Statewide. Busy with new applications.
- Cory – Same as Charae, Helping Hands of Vegas Valley has new respite funds for those for 60+ who do not have dementia, even for those younger than 60 years old. Demand is strong.
- Barry – Nevada 9-8-8 hotline for mental health is going live. Hoping it will be successful here.
- David – Yazmin is getting lots of referrals for emergency respite. Congregate meal site at Nevada Senior Services is only one open right now. Pretty good turnout.
- Cory – Another stand-alone congregate meal site will hopefully be opening soon.

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.