Nevada Lifespan Respite Care Coalition
Community for Respite Meeting
March 18, 2022
Time: 9:00 a.m.- 10:00 a.m.

Join on your computer or mobile app
Click here to join the meeting
Join with a video conferencing device
192425125@teams.bjn.vc
Video Conference ID: 117 025 427 6
Alternate VTC instructions
Or call in (audio only)
+1 775-321-6111,,771076377# United States, Reno
Phone Conference ID: 771 076 377#

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, Amy Dewitt-Smith, Deidre Manley, Jana Borden, Tori Diego, Kathy Doyle, Charae Wamsley-Gipson, Barry Gold, Jodi Collins.

1) Introductions and Check-In:

As a kid, what did you want to be when you grew up?

- Charae – I really wanted to be a dentist, after my first tooth had to be pulled. I worked at a dentist office, but it just didn't pan out as I got older.
- Cory – I wanted to be a veterinarian. I even went to school, worked at a veterinarian's office, but it just didn't work out.
- Deidre – I wanted to be a nun just because my role model for working with children were nuns. My mother pointed out that I didn't have the right personality for being a nun.
- Barry – Sometimes I still feel and act like a kid, but when younger I wanted to be an astronaut. That was a very exciting thing to me.
- Jana – I wanted to be a police officer and I pursued that, but it took so long for them to get back to me after background checks and such, that life took me in a different direction.
- Kathy – I wanted to be a nurse practitioner and actually I did for a while because of my military background. And I have continued to do some form of nursing through caregiving.
- Tori – I wanted to be a pediatrician, and then switched to pediatric nurse, but I failed my first biology class. So, I switched to psychology.
- Yazmin – When I came to this country, I was in awe of the ESL teachers. So, I wanted to become one for the longest time.
- Amy – As a kid native to Nevada, I wanted to be a cocktail server and I did while in college. I also wanted to be a teacher and a school bus driver – to work with children. Now I have 6 children of my own and one more on the way!
- Jodi – As a kid I wanted to be a veterinarian, but as I entered biology, I decided nope. I didn't really like the dissecting and stuff, so I was a teacher and speech pathologist.
- Cheryl – My first childhood wish was to be a Disney princess, but later I decided a dental hygienist

sounded like a good career until I realized I would be spending time in people's mouths, and it lost its appeal.

Many of our family caregivers were something else before they were a caregiver to someone who had special healthcare needs or disabilities.

As we talk about caregiver assessments, we'll be talking about identifying caregivers and where they are at in their caregiving career and what they need to be successful in their role. This is different than a program evaluation or outcome measures yet lead to understanding caregivers better. But what does this feel like from a caregiver's perspective?

NLRCC has a responsibility to identify caregivers needs and advocate for them at the state level and promote services and supports that meet their needs. The transition into the role of a caregiver isn't the easiest one.

Cheryl – As a caregiver, I delivered a child who had to stay in the NICU, and I was discharged by a social worker and given a handful of brochures and information with my referrals. I had lots of doctors who were caring for my son, but no one asked me how I was doing. When I started having panic attacks, that encouraged me to reach out for peer supports, respite, and other services.

2) Challenging Questions/Discussion –

Are assessments seen as the way to identify caregiver needs or used to judge how they are doing in giving care? Do caregivers who participate in an assessment feel acknowledged, valued, and better understood?

Cheryl – We may have some stress tests but is anyone using caregiver assessments? Will it assess if I'm impacted enough or assess how I am giving care. We don't have systems in place to really judge this – maybe we should talk about where we

Barry – From the professional realm, we look at caregiver assessments about what they need and how we can help. It is "what kind of a job are they doing" but I am working with ADSD to find best practices from other states that incorporate caregiver assessments. I have been in situations where they come to check up on you – and how that feels is important to realize. Inherently those visits are to find what extra help do you need and maybe we're not providing what we could, but it must be from their perspective of what they need and want. I have seen that we can sometimes shove services down their throats, and they don't want it. Gave me something to think about.

Cory – We do assessments. A pre-survey when application goes out, a caregiver post-survey about how they feel after receiving respite. It includes satisfaction about agency and provider they worked with. I never thought about caregivers feeling judged because that's never crossed my mind. Give me a little bit of pause. We are truly there to help them, to validate them. They express themselves through the write-in information.

Amy – We have basic pre- and post-survey. We could ask better questions and get information that values caregivers and improves the way that we support them. In the pre-survey, there's the emphasis on demonstrating need and so caregivers feel that pressure to express that. Once they have been receiving care, do they feel like it's okay to express that they are not okay? To still say that they still have needs, to say that "it's still really hard" or I have these unmet needs. Relief looks different for everyone. Any way that we can ease that discomfort to caregivers when we ask questions would be important. Love to try out new tools so we can do better.

Charae – We get so focused on seeing an improvement in the caregivers and how they perceive their stress levels or how much time they have for own activities. What if there isn't a difference on a pre- and post- survey? We share pre- and post- survey results to legislators and funders to hopefully promote respite and other services. But what if negative responses show that caregivers need even more respite, not the minimal/limited amount of support they have received. Negative results might also be important to the message that, yes, these services are helpful, but they are not enough.

Jodi – New to group but a caregiver of adult son with disabilities. Never had someone ask me how I was doing. The surveys that we get from the company we use is more about "how is the care recipient doing?" I think it's a great idea. I wish they would do more. This is something that can be taken to the legislators. Retired as a

teacher, immediately PCA services were going to be lost because I as a caregiver was available now to provide care. They were not looking at the mental health aspects. We get more sleep when someone comes in to help our son. Even if I'm not working, the breakup of my sleep doesn't help me care for him the rest of the day. Immediate loss of that support was going to impact my mental health.
Kathy – I have been going through stuff with ex-husband but got in touch with Veteran's experience. They listen and let you vent and offer suggestions about what you could do. I want the doctor to know what's been going on with the various doctors/hospitals and found the doctors put stuff on record that was not shared with others. Resulted in a misdiagnosis. Can you feel like you can advocate for someone in need?

An effective caregiver assessment should approach care issues from the caregiver's viewpoint and culture – a move toward more person- and family-centered care. Do caregivers benefit more from speaking to a live person or would a written form or online survey be more private/anonymous for sharing a caregiver's concerns?
Cheryl – I don't know if I would have wanted another appointment when I had so many, and I might have felt that filling out the form they put in front of me was so that they could check a box of something required of them. I personally like to have time to talk and hear all that is going on, and then ask, "how are you doing?" and respond to their specific needs in that moment. It might be easier to gather data from a survey than an interview.
Cory – I send surveys by mail/email but when I can talk to caregivers, I can hear what's going on and offer options. Private survey might avoid the feeling of being judged. Not feel pressured or that there's a right or wrong answer. Sometimes we get negative feedback, and the anonymous response is truer and
Amy – Good conversation to rethink all of our processes. We do monthly home check-ins and staff have a form for conducting an interview. I haven't thought about sending caregivers the form. On another program, I do think I get more frank comments on the form they complete themselves. Not looking at someone while responding to questions. For me personally, getting another form to complete with all my kids and responsibilities gets to be too much. To increase the rate of getting information back, we have been doing the interviews but now I am wondering if it is anonymous enough for them. Need to think about what caregivers might prefer.
Cheryl – I think we can see that there are some pros and cons to how we conduct caregiver assessments. As we move towards person- and family-centered care, what does it feel like for them? What does another survey make me feel? Is it going to be lost in a pile of things I need to get done? If it comes with an application, is it really something I need and will use? Is someone going to ask me anything about my needs?

Do caregiver assessments result in a plan of care where family caregivers receive appropriate support services tailors to their specific needs – such as care consultations, education and training, counseling, support groups, and respite care? If not, how do we get there?
Cheryl – No matter how we conduct the survey, how do we respond to it? Does it translate into a plan of care?
Charae – When we onboard someone, we do a care consultation and get an opportunity to hear about their situation to the level they are comfortable. Then we can make referral or offer resources and tailor our recommendations. That's our opportunity to set up a care plan. We do quarterly check-ins for a verbal opportunity for an update on their evolving situation.
Amy- Initial assessment is tied to care plan but sometimes follow-up is too "we got that form done." We can always improve, as we learn about a family, to go back and review care plans. Make more direct links to care plan revisions.
Tori – We have pre- and post-surveys as well as a program evaluation for our Powerful Tools workshop. If there's a community resource they have heard about, but is not familiar to staff, it is referred back so I can connect them to the resources that they need. We also have a caregiver support group and our senior care counseling program that connect them by phone/virtually. We promote other programs because people just don't know about them. We get siloed and I feel sharing and making those connections is part of what we should do. I feel we should re-evaluate everything we are doing and maybe get better questions because I didn't really think about them and how they might feel judged.
Cheryl – I felt like the professionals would look at me at judge whether I had my act together. I got information on peer support but thought I might have to go through a social worker who facilitated the support. When I called and talked to another caregiver, I relaxed and could accept some of her suggestions, when I might have had a wall up if I was talking to a professional who might evaluate me. When I talk to families, I can always say I am a

caregiver and get past reservations they might have in sharing information.

Cheryl shared a couple of evidence-based instruments for caregiver assessment used nationally to look at and explore. A point-in-time assessment that gives recommendations but not resources could still help programs flag needs for referral and discussion. The recommendations were for doctor check-ups, respite, and peer support.
Amy – It might be important to have a statement that caregiver responses will not affect their eligibility for services. So that they are not afraid to be frank.
Cheryl – These do address physical, emotional, mental, financial, and natural support aspects of caregiving.
Tori – Leave forms as anonymous but have a way for follow-up if they want it. Then they can get some response from their cry for help.
Cheryl shared another form being used around the nation. This form views care more broadly, rather than a diagnosis-eligible approach. More financial burden, disagreements within family, preparation and other topics covered. Employment situation is captured. It also has questions to request follow-up contact. The length of a survey tool also needs to be considered.
Jana – I have interview questions to send you once I get approval, to compare with these versions.
Amy – I felt like the first one was simple but didn't really "dig in" and the questions were subjective. I like the second one for more objective and concrete examples and uses a Likert scale (not narrative) for quickly assessing more accurately the situation. It is long but the Likert scale might not take a long time to fill out.
Cheryl – If you have instruments that even have one or two questions you like and would recommend, please send them to me.
Cory – Do you want our surveys that we use? See what's good or bad. Share them to the group.
Cheryl – Pick questions that you think are valuable and have purpose behind them. Ones that help a caregiver feel recognized/acknowledged/valued for their role. Caregiver assessments would ultimately develop a relationship with agency/provider, not be a check-it-off process, and would give us actionable data that would help us serve them better.

3) NLRCC Board Update
    - Outline for State Plan on Caregiver Support approved.
    - Next Board Meeting April 18, 2022, 10am-12noon, agenda and meeting link [Home (nv.gov)]
    - Next Community for Respite Meeting is THURSDAY, May 19th at 9:00am, discussing where a caregiver assessment would be used, the input point to place it, rather than the assessment itself.
4) Group Updates - none