

New Mexico Direct Caregivers Coalition

Lifespan Respite Summit March 1, 2017

Post-Event Notes

Lisa has two daughters, one who had half her brain removed at only 6 months old. The portion of her daughter's brain that was removed is the portion that regulates behavior. Her daughter would be kicked out of the programs for using inappropriate language around the other children. Lisa cannot discipline her daughter for her inappropriate behavior because her daughter doesn't recognize it and doesn't care.

Lisa has tried to place her daughter in multiple different respite care and daycare programs but leaving her daughter in drop-off programs has not worked.

Lisa needed another solution. She received funding for respite care. When she was searching for a respite provider, she was approached by the Educational Assistant (E.A.) who was assigned to her daughter at school. This person asked to be hired as the daughter's respite provider for the summer. Lisa assumed that the educational assistant had been vetted by the school and hired the E.A. to care for her daughter. After hiring her, she started to notice that her daughter's behavior had changed. Her daughter's teachers also noticed changes in behavior. Originally the change of behavior was brushed off, since her daughter sometimes had odd mood changes. When asked, the daughter would say nothing was wrong, but it was discovered that the E.A. was abusive toward Lisa's daughter.

Lisa's dilemma is not unlike many New Mexico parents of children with disabilities. Often, it is not a matter of IF, but WHEN, a child will be abused or manipulated, especially when programmatic steps to prevent such instances is not in place.

Manya Pungowiyi worked as a Developmental Disabilities Support Specialist for many years. Her life completely changed 17 years ago when her adult son, Bryce, suffered an auto accident that left him completely disabled. Since that accident, Manya and her husband have used up their retirement funds to care for Bryce 24 hours/day. Manya has not taken a single day off work in 17 years. Her son suffers seizures and so Manya and her husband take turns staying up all night to monitor him. They must also be available for him throughout the day. Manya says that fatigue is the number one issue facing caregivers like her. She is 69 years old and the toll this work has taken on her health is immense. She herself has disabilities. She relies on paid caregivers for respite. However, in the last two months, her bather and overnight caregiver quit and she has had to step in to do additional work as Bryce's caregiver. The agency she works with has sent temporary caregivers who are not trained in the highly specialized needs her son requires. The need for credentials and specialized training of reliable respite caregivers is crucial for Manya and her family. She is very tired and when she has access to respite care, she uses it to sleep.

Morning Breakout Session Discussions

Blue Group

Challenges and barriers caregivers face:

- fatigue
- connection between lack of respite and issues of other stresses

- education of all family caregivers so they all can help
- medications, what to do.
- need to prepare for emergencies, good communication, backup plans, contingency plans
- health literacy (health education)
- callers and consumers need help navigating system
- adequate funding for services including nursing care, community-based programs, access for families in culturally-competent ways
- job bank or registry

Red Group

Barriers and needs include:

- There are problems in rural areas getting information to Native populations in ways they can access. Even in rural areas where there may be available respite care have problems in that people don't know how to access.
- Information on resources must be understandable in ALL areas especially in Native communities. Once people are turned "off," they do not even pursue the available resources. In rural and Native communities, people are still overlooked or ignored. Natives and rural residents can be supported in building their own businesses. We should include ways for rural residents to keep money in their own communities.

Solutions:

- Get Letter of Agreement for tribes to get resources
- Universities that hire interns (occ therapists and physical therapists) could use respite care hours as a way to pay off student loans. We need to collaborate, not compete, so that the consumer/member/care recipient is served as well as the caregiver.
- One solution is for building out Train-the-Trainer programs so that people in their own communities are seen as the ones with expertise.

Yellow Group

What systems already exist?

We do not yet know the universe of respite options available because there are questions we don't know how to ask yet. We do not know array, eligibility, benefits of all that might be available to New Mexicans.

(Another group in afternoon shared) "You cannot coordinate services that don't exist. You also cannot coordinate programs if you don't know they DO exist."

- The MS Society is able to use and give out state and Federal money (for grants?) – see Vicki Kowal who is also a family caregiver herself.
- One of the problems is that we have inconsistency in provision of respite care, theft by caregivers in homes, loss in continuity of care, lack of cultural competence, untrained providers.
- NM Parkinson's Coalition said that training of caregivers for care recipients with Parkinson's is essential. (gave example of medication required 4 times/day). Respite affects the quality and continuity of care.
- Who is missing from this conversation? PACE, behavioral health, mental health, American Heart Association, Gov Commission on Disability, SILC, Disability Rights NM, Delfy Roach and TBI community. elder law (someone noted importance of Power of Attorney, another noted guardian ad litem).

Afternoon Breakout Session Discussions

Red Group

“No Wrong Door” No caregiver should have to make more than two phone calls when she/he needs help. Of those programs available at no cost, use the Train-the-Trainer element. It’s good for communities and demonstrates cultural competence. The Train-the-Trainer aspect actually provides respite itself. This approach may also work within faith community.

Yellow Group

- As for sustainability, bring in the right partners but also work with what already exists in communities where there are already interested people who need help.
- ADRC shared that there is a list of 4,000+ resources in NM from which the respite stem could build on
- Barrier: Caregivers can often be in denial about the need to take a break. We must make it OK and remove the stigma of asking for help. We should help people know and understand that the issue is multi-generational and that we all sometimes need help.
- “Our goal today was convening a diverse group in order to share and talk about a common goal of the need for NM respite care system.”
- We need to tap volunteers and use their desire to want to give back
- How do we build sustainability? Through advocacy, fundraising, find legislative champion, hold annual summit on respite care.

Blue Group

How do we Build collaborations? We are off to a good start today.

- We need access to information on available services. We also need to implement a “No Wrong Door” at the local level.
- We need training and standardization and must have multiple levels of credentialing to serve a variety of needs
- We need to involve families in all trainings
- We need to encourage care recipients to attend training
- We need to provide respite care at all events as a way of demonstrating the need for it
- Use Project ECHO as a way to get information to local communities (PRO has begun using ECHO and conducting training this way)