Arizona Respite Network – Quarterly Meeting

Meeting Notes October 19th, 2021

Vision: All family caregivers in AZ will have access to respite care services when needed, including during emergencies.

The Arizona Respite Network is hosted by the Arizona Caregiver Coalition, the Arizona Department of Economic Security (ADES) Division of Aging and Adult Services (DAAS), and the Lifespan Respite Committee. It is an initiative under the Lifespan Respite Program Grant from the Federal Administration for Community Living (ACL).

1. Welcome and Background – Jutta Ulrich, Executive Director, Arizona Caregiver Coalition, welcomed all attendees and provided context for this meeting. An advisory committee for the Arizona Lifespan Respite Grant had been meeting since fall 2019. The committee identified needs, gaps and opportunities which helped inform the 2020 Lifespan Respite Grant. This included a need for emergency respite funding and procedures, a need to identify providers of emergency respite, and the need for more public awareness. Also, the committee saw an opportunity for new program development with grant funding. The formation of the Arizona Lifespan Respite Network was proposed in order to expand effectiveness.

2. Review of Vision – Jutta Ulrich and Lita Nelson, Family Caregiver Support Coordinator, DAAS, reviewed the vision and goals of the Lifespan Respite Network (see attachment). All Network participants are invited to provide feedback on the mission and charter statement by writing to info@azrespite.org.

3. Activities in progress
   a. Cat Trobaugh, Case Management Supervisor, WACOG Area Agency on Aging, explained the plan for creating a list of vetted respite providers, including overnight and emergency respite. Letters have been sent to providers throughout the state, inviting them to contact us if interested in being placed on the list. The list will be posted on the website of the Arizona Caregiver Coalition, accessible by the general public. Providers can contact us at info@azrespite.org.
   b. Lita Nelson reported that ADES-DAAS is working with Area Agencies on Aging on developing policies and procedures for referrals to emergency respite funding. A limited amount of funds is also available through the
current Lifespan Respite grant, and the referral process will include procedures for referring to the Arizona Caregiver Coalition, including a self-assessment to be shared publicly for direct family caregiver access. Depending on the overall score, a referral can be initiated.

c. Jutta Ulrich provided an update on the status of a caregiver toolkit, a workbook with checklists to help caregivers be prepared for situations when respite might be needed on short notice. The AZ Caregiver Coalition will pilot the toolkit in November and December.

d. A funding opportunity through mini-grants for community-based organizations had been established earlier this year. Jutta Ulrich reported that one project was successfully completed by a faith-based organization and approximately six grants up to $3,500 per project are available.

4. Next steps and Action Items
   a. We will schedule quarterly meetings with committee reports in January, April, July, October of 2022. These are open to all organizations and individuals with a stake in caregiver respite in Arizona. Schedules will include updates on projects, informative presentations, and discussion of issues.

   b. Discussion of concerns and priorities. Scott Hawthornthwaite, Area Agency on Aging Region One, and Cat Trobaugh reviewed ongoing work and asked participants to share their ideas and concerns.
      1. Graciela Mera, Alzheimer’s Association, stated a challenge is to get family caregivers to actually use the respite funds. Even when a provider is used, the family caregiver often stays rather than taking time for themselves. The Alzheimer’s Association respite is similar to the Friends & Neighbors Program offered by Area Agency Region One and Pima Council on Aging.
      2. Lita Nelson suggested we could compile testimonials from caregivers about the benefits of respite and conduct continuous research for gaps in services as well as networking to increase access to other respite services or resources.
      3. Courtney Allen, Benevilla, said there is a process to be eligible for Adult Day Health Center services, including an annual TB test and a medical note. This can affect access to respite.
      4. Brandon Baxter, Program Manager at the NACOG Area Agency on Aging, suggested we create a short self-assessment and put it on the AZ Caregiver Coalition website. Questions might include: Are you the only caregiver? When do you get a break? What do you do to have fun? Additional outreach is needed with potentially placing ads in publications such as Spotlight and Senior Directory.
5. In response to a question if the Latino community can be served if legal residency cannot be documented, Lita Nelson stated the intake process does not ask about citizenship.

6. There was discussion of potential duplication of services. Typically, a caregiver can receive respite from only one source at any given time. We may need to review if an exception can be made for emergency respite, e.g. by placing the individual on a wait list in one program and then offer emergency respite.

7. Specific issues identified as priorities:
   a) Emergency respite funding
   b) Implement the emergency respite toolkit and checklist
   c) Shortage of direct care workers (DCW)
   d) Outreach and publicity of respite options

8. Subcommittees will continue work:
   a) Executive committee = heads of subcommittees - Jutta
   b) Advisory committee for the grant – AAAs, ACC, DAAS – Lita Nelson
   c) Respite provider list - Cat Trobaugh – looking for more committee members
   d) Mini-grants to develop respite programs
   e) Outreach and publicity – looking for committee members

Attendees:
Jackie Edwards, Intertribal Council of Arizona
Thomas Winkel, Arizona Coalition for Military Families
Barbara Diehl-Rouen, ADES Division of Developmental Disabilities
Shawn Thompson, ADES Division of Developmental Disabilities
Ginger Fligger, Pinal-Gila Council for Seniors
Dee Person, Be Connected Engagement Program
Mary DeGuzman, VA Caregiver Program
Brandon Baxter, NACOG Area Agency on Aging
Cat Trobaugh, WACOG Area Agency on Aging
Scott Hawthornthwaite, Area Agency on Aging Region One Inc.
Graciela Mera, Alzheimer’s Association Desert Southwest
Paulina Serna, Raising Special Kids
Karen Enriquez, SEAGO Area Agency on Aging
Sam Bandiera, Pima Council on Aging
Lita Nelson, ADES Division of Aging and Adult Services
Courtney Allen, Benevilla
Jan Tankersly, Oakwood Creative Care