Notes from November 7, 2012 Conference Call with Lifespan Respite Grantees

Greg Link kicked off the call by stating the purposes of the call:

- An opportunity for the grantees to talk to one another about challenges and successes
- An opportunity to hear from Jill about the direction the new ARCH resource center is going in

He introduced Erin Long from AoA who will take on a greater role with managing lifespan respite.

Lifespan Respite Status

Greg then gave an update on the status of the Lifespan Respite program:

- FY2012 marked the 4th round of grants
- 30 states + DC received awards for 3-year grants
- Expansion grants were awarded in 2011 & 2012 and these will be focused on providing gap-filling services
- In 2012, 7 states were awarded integration & sustainability grants in order to allow 2009 grantees who have already developed their Lifespan Respite infrastructures to take the effort to the next level and expand the scope of work they are doing in areas such as data base development, state respite plan development, and marketing.
- ARCH, in addition to providing TA, will be helping grantees think through data reporting. They’ll be coordinating that plus a comprehensive look at the current status of respite research and how we can make the best use of that research.

Jill Kagan reported there is no news on Lifespan Respite reauthorization. She said the current bill will have to be re-introduced in the new Congress.

Greg is working on the 2013 Program Announcement. He remarked that some of the 09 grantees put in for no-cost extensions and should be hearing shortly about that. Other 09 grantees ended on time.

ARCH Activities

Jill introduced upcoming activities of the new resource center. ARCH will be providing many of the same supports, but will be expanding into the area of performance measurement and stimulating respite research. This first call will be the beginning of a series of calls with grantees on specific topics.

ARCH entered into a new cooperative agreement with ACL/AoA to provide services as the new Lifespan Respite Technical Assistance Center. The main objectives and the corresponding activities are to:
Obj 1) advance the practice and delivery of respite services for all ages and special needs populations through technical assistance tools. Activities will include:

- **Need Assessments**: used to inform fact sheet and webinar topics. Please complete the training/TA needs assessment sent out last month.
- **Grantee Activity Tables**: These are summary tables of Lifespan Respite grantees’ activities and state respite coalition and ADRC roles. Tables are used for training, for educating policy makers and the public, and for sharing among grantees. Please respond to Maggie Edgar’s request to review your state table.
- **Sustainability Activities**: working with the Finance Project to develop new tools and future TA activities – please provide specific suggestions.

Obj 2) provide effective training and peer-to-peer networking opportunities. Activities will include:

- Webinars – at least two to be held this year
- State Lifespan Respite Summits: LA, AR, CO
- Regular Topical Conference Calls
- Planning for National Conference and Grantee Meeting next year -- hope to finalize location in the next two weeks.

Obj 3) develop a performance/data collection plan to help sustain Lifespan Respite programs. Activities will include:

- **Convene Data Workgroup**: In collaboration with AoA, ARCH convened a Data Workgroup made up of researchers, data experts, federal agency representatives, select Lifespan Respite grantees and partners, and practitioners who will assist AoA with the development of a performance/data collection plan. Group will focus on systems development measures. Jill referred to table of suggested outcomes sent around to grantees/partners in early September for their input.
- **Establish Data Collection Tools Repository**: A variety of data collection tools to assess program outputs, respite service satisfaction, family caregiver and care recipient outcomes, and other indicators will continue to be collected and lodged on the ARCH website. These tools will be used to inform the efforts of the Data Workgroup to develop a performance/data collection plan. In collaboration with AoA and the Workgroup, ARCH will continue to work with states to assist them in the development of such tools and share this information with the Lifespan Respite Network as appropriate.
- Casandra Firman and Ray Kirk, authors of the ARCH manual, *Evaluating and Reporting Outcomes*, will be working with us and will be available to provide some TA.

Obj 4) collect, synthesize, disseminate and stimulate respite research. Activities will include:
• **Literature Review and Annotated Bibliography:** Criteria for inclusion of relevant research in an annotated bibliography of respite research will be developed and the annotated bibliography will be completed early in year 2.

• **Expert Research Panel:** In collaboration with AoA, ARCH will convene an Expert Panel on Respite Research composed of leading researchers and practitioners in the field of respite and family caregiving across age and disability groups, and foundation representatives. The Panel’s purpose will be to develop recommendations for future respite research. Panel’s responsibility will be to review the respite research and make recommendations for future research.

• **Web-based Database of Promising Practices in Respite Services, Research, and Delivery:** ARCH frequently receives requests for “model” respite programs, service delivery mechanisms, and evidence-based respite practices for specific populations. In a limited way, such practices have been highlighted in ARCH fact sheets, guidebooks, and newsletters. ARCH proposes to develop a more centralized on-line repository of respite research and service promising practices that will complement and link to the Family Caregiver Alliance’s Innovation Clearinghouse. Entries will be drawn from the literature review, from the ARCH Advisory Committee, from the Expert Research Panel, and from experts and practitioners in the respite network who will be invited to submit programs and research to populate the database.

**Grantee/Partner Discussion:**

Greg proposed the following 2 questions to conference call participants:

1) What trends in your state have the most potential for your LRP?
2) What opportunities do you see for LRP to expand?

Group discussion:

Jeff (NV) – NV is successfully integrating 3 programs – LRP, Alzheimer’s (ADSSP) grant and Chronic Conditions Management Grants

Joyce (TX) – recognizing the demographic changes within the state, especially among the Hispanic population, how do we market to those populations who do not identify as caregivers? What have other states done? Also requested TA on evidence-based training for family caregivers of younger people with disabilities.

Jill (ARCH) - commented on a workshop presented at the International Respite Conference that addresses Joyce’s request for evidence-based caregiver training. Presenters discussed a modification of Powerful Tools for Caregiving that targets parents of children with disabilities. It is being piloted in NH and the national organization plans to release the curriculum next year. Georgia’s Division of Aging Services collaborated with their developmental disabilities agency to modify the evidence-based TCARE (Tailored Care) program for the aging, which is a process that assesses caregivers’ needs
and develops a service plan, to be used with family caregivers of individuals with developmental disabilities.

Susan (SC) – said they have better luck using the term “family caregiver” as opposed to just ‘caregiver.’

Peaches (CT) – They partnered with a local university Spanish Department and a nursing student to find out what is most acceptable to the Hispanic community for marketing respite messages. They found out that if there’s any hint the caregiver might be tired and need a break, that isn’t acceptable. What is acceptable is “what can we do to help you?” What was so beneficial for them was the opportunity to travel around the state and hold forums. They found how little is known about respite but also the great need for respite for grandparents raising grandchildren without legal guardianship.

Kathy (RI) – collaboration with lots of different state agencies, especially as the state is developing its Alzheimer’s plan, long term care groups, Money Follows the Person Rebalancing Initiative. Chairing a subcommittee on family care and respite.

Jennifer (NJ) – With our Systems Integration grant, looking at Care transitions; at trends related to Medicaid reform and aging in place. It would be helpful to talk about respite in a managed care environment. Could use TA on respite and Medicaid managed care. Also the benefit of the Medicare hospice & respite benefit and how to integrate Lifespan respite into end of life initiatives.

Linda (DC) – accomplish the integration of hospice and respite by sharing information between these groups at coalition meetings

Jennifer (NY) – we’re working on consumer directed respite and Lifespan respite provides and umbrella across agencies

Susan (SC) – the impact of the Affordable Health Care Act on respite as it rolls out

Amy (MA) – Caregiver public awareness campaign trends; the TA center could help with that

Val (CO) – ditto to Amy’s comment, especially with all the different types of respite

Alicia (NC) – trying to show the value of and the overall savings in providing respite. Have other states studied cost-effectiveness? How can we tackle it state by state and nationally? How has NFSP documented that?

Jill (ARCH) - MA Division on Aging will be rolling out new data from a home care survey of 35,000 family caregivers next year.

Jennifer (NY) – mentioned a survey on caregivers in NFSP, a random survey, from which they may be pulling out some data on respite.
Java (AL) – *Sharing the Care* has revealed that many people are not happy with respite they receive through the Medicaid waivers, but are afraid to raise issues. Would like to figure out a way to facilitate a discussion between family caregivers and state Medicaid agency.

Sharon (NE) – respite under Medicaid waivers in NE is all consumer-directed.

Greg (AoA) – it sounds like it depends on the state’s approach.

Kathy (RI) – would like to see LRP become a regular, consistent means of funding. That would require a change in statute and in meaningful funding.

Peaches (CT) – recognizing the gap population which isn’t the very wealthy or the very poor. We’d like to use a volunteer base and by doing so you can reach people at all different financial levels.

Greg (AoA) – There is a cost associated with volunteer programs, including training, etc.

Kathy (SC) – we tried to work with AmeriCorps and also the faith community. The problem with AmeriCorps is that they actually get paid. It’s nice to develop a cadre of respite providers along a lifespan continuum. Work with a school to develop a basic level of training and a certificate program for respite providers in a formal way so they can be reimbursed through Medicaid.

Peaches (CT) – create a work force

Sharon (NE) – working on developing emergency respite standards. Partnering with a local university to do first responder training for respite. Developing an emergency management major via a university that is connected with other first responders. It will elevate the status of respite.

Greg Link thanked everyone for joining the call and the call ended at 4:30 PM EST.