

# Lifespan Respite Grantee/Partner Learning Symposium

## Summary Notes

August 31, 2015

8:30 am – 4:10 pm

*Holmead Meeting Room, Washington Hilton, 1919 Connecticut Avenue NW, Washington DC*

### Introductions

- Welcome and acknowledgment of attendance of two members of the ARCH Lifespan Respite TA Center Advisory Committee, Laura Weidner, NMSS, and Miriam Rose, Benjamin Rose Institute on Aging, and Kevin Foley, Lifespan Respite federal project officer, Administration for Community Living.
- Thank you to Mary Jo Alimena Caruso, PA Respite Coalition, and Linda Irizarry, DC Lifespan Respite Program, for their service on the planning committee for today's events
- Recent news updates
  - ARCH was recently awarded funding to continue as the Lifespan Respite TA Center from ACL
  - One new state, FL, was awarded a Lifespan Respite grant last week

### Logistic Announcements

- Included in symposium folder: Symposium agenda, infographic with new statistics from AARP on the cost of family caregiving- \$470 billion dollars annually, speakers' PowerPoint presentations, symposium participant list, TA Needs Assessment and Evaluation forms to be completed by the end of the symposium

### Bring, Brag, Borrow

Objective: Bring, Brag and Borrow is an opportunity to share knowledge and resources about activities occurring in different states. One spokesperson from each state was given the opportunity to discuss a successful development in their states efforts, bring a resource with them and explain it, or ask to borrow ideas to address local issues. Materials for sharing were located in the conference room on the "Share Table" and will be posted online with permission.

- **Alabama:** Spokesperson Melissa Terry, AL Lifespan Respite Network. Emergency Respite initiative. Marketing: posted information on website, provided information to area agencies on aging, contracted with two different home healthcare agencies but also had voucher system for caregivers. Usage between two types of care was spread 50/50. Vouchers are encouraged due to better quality of care. Program serves any disability from any age. Guidelines are posted online.
- **Arkansas:** Spokesperson Susie Keesling, AR DHS-Division of Aging and Adult Services. Described Respite Awareness Day initiative. After receiving grantee award in Sept 2014, held

awareness day in late October. Distributed Save the Date flyers to state organizations and governor issued a proclamation for awareness. Marketing materials included a DHS press release, t-shirts for coalition members, buttons for attendees, a factsheet infographic, and an information booklet. Logo for materials was designed by a pro bono graphic design professional. Speakers included legislators, family caregivers. October 29, 2015 will be the next awareness day.

- **Colorado:** Spokesperson Lynn Robinson, CO Easter Seals. Main focus has been work with legislature. A Respite Legislative Task Force was formed through state statute. Goals include to document availability of information and improve clarity of informational materials. State programs include legislative creation of a fund that uses money from crimes committed against vulnerable populations to fund respite. Updated website with 5 pages of partner websites and referral links.
- **Delaware:** Spokesperson Nancy Ranalli, Easter Seals, DE Lifespan Respite Network, developed a new flyer to outreach to more people who need respite through their voucher program. Currently have 110 on a waiting list. State has identified need to help caregivers get respite in different / non-traditional ways. Funding is limited and there needs to be a different options for respite, other than their voucher program, so that people do not get turned away now that the word is out and more people are seeking services.
- **District of Columbia:** Spokesperson Linda Irizarry, DC Office on Aging. Working on developing volunteer respite program in mid-September. Holding local Lifespan Respite Conference in September. Uses online respite chat line to enable networking between caregivers.
- **Idaho:** Spokesperson Pam Catt-Oliason, ID Commission on Aging. Held July Lifespan Respite summit for 80+ people. Highlight from summit: small-group discussions for attendees. Each small-group discussed an issue and potential solutions to implement.
- **Illinois:** Spokesperson Rebecca Galvan, Illinois Respite Coalition. Illinois had not had federal Lifespan Respite funding for past 2 years but state funding beginning April 2015 enabled set up of new website, referral services and emergency respite. There is no current funding for respite in Illinois because of governor's current budget.
- **Iowa:** Spokesperson Julie Bergeson, IA Dept. on Aging. Emergency respite voucher is a success. Individuals have choice of provider. Rebuilding coalition and asked Colorado Respite Coalition to share their success. Iowa is having to deal with legal issues related to managed care. First annual respite conference is scheduled for November 10, 2015.
- **Massachusetts:** Spokesperson Emily Kearns, MA Lifespan Respite Coalition. MA recently held their 3rd Care Conference attended by 300+ people. Conference featured a panel of "social entrepreneurs"—caregivers who created programs and businesses to fill gaps in needs they experienced. Examples include a dance studio for individuals with disabilities and a restaurant serving families with a loved one with autism. There was also a panel of male caregivers at the conference. Most conference goers appreciated the perspective of male caregivers. More resources are needed to give a voice to and support the needs of male caregivers.
- **Montana:** Spokesperson Kerrie Reidelbach, MT Office on Aging. Shared cinch bag as a take-home from first held Lifespan Respite summit held in conjunction with the Governor's

Conference on Aging. Summit included a roundtable discussion of 30 people. Used it as opportunity to get new members as well as share information. Also created brochures for new voucher program that begin July 1. Used Kit Kat bars to market the phrase "Take a Break" tied on with a ribbon to an information card about respite resources. Legislative action will be next year's focus.

- **Nevada:** Spokesperson Jeffery Duncan, NV Aging and Disability Services Division. State has created a telephone-based caregiver support program, called the Care Consultation program of the Rosalynn Carter Institute for Caregiving. Program will empower caregivers to care for themselves, take breaks that they need, and access resources remotely. Program will address needs of caregivers who have no support, especially in rural and frontier areas of the state and empower them to get training, care resources, and self-care resources from home.
- **New Hampshire:** Spokesperson Felicia Anfuso. New Hampshire Lifespan Respite Coalition hired her as an AmeriCorps VISTA volunteer to serve as program coordinator for the coalition now that Lifespan Respite federal funding has been expended. They are actively promoting their online provider registry developed with Rewarding Work. In process of creating a business card (2-sided) with information about the program, information on the website. New coalition website. Purchased flash-drives with preloaded promotional materials so that other professionals can print out materials as they need. Enables NH to spread promotional materials without cost of printing materials.
- **New Jersey:** Spokesperson Eric Joice, NJ Lifespan Respite Coalition and Epilepsy Foundation of NJ. NJ completed a survey of 1100 families using respite. Interns created respite brochure with information. Used lobbyist to gather leaders to listen to needs of agency, gathered large crowd to draw attention to legislators. Creation of a respite task force has passed assembly, due to be signed in January.
- **North Carolina:** Spokesperson Alicia Blater, NC Division of Aging and Adult Services. Focus on taking strategic planning survey results and information gathered at Lifespan Respite State Summit to create a business plan for state coalition and a strategic plan for sustainability. NC had innovative program to integrate caregiving into other existing state programs by educating professionals to talk with caregivers about respite. They are making available their learning modules for this purpose to the ARCH Network at no charge for a limited time. There is a UNC Chapel Hill web link that anyone can use to access the 5 learning modules focusing on general information on caregiving, assessment, planning, and respite implementation resources. Includes several links to resources. Modules aim to help identify resources outside of conventional sources of support. Flyer about modules in ARCH folders.
- **Ohio:** Spokesperson Angie Lee, Easter Seals and co-chair of Ohio Respite Coalition. May 2015 survey to caregivers and providers to determine service gaps. 2000+ responses received from all 88 state counties. Survey showed lack of providers was a bigger issue than lack of funding. Mini-grants for volunteers to develop volunteer caregiver network. Working on developing toolkit for that (recruitment, training, marketing models).
- **Oklahoma:** Spokesperson Karen Poteet, OK Aging Services. OK has partnered with 5 different agencies to provide respite statewide. Partnered with U of OK Sooner Success program which

assumed responsibility for administering the respite voucher program. Provides \$400 in vouchers per quarter for respite relief. Has access to respite provider training opportunities for free. Other 4 agencies include an adult day center providing overnight care, a mobile care respite initiative that provides 3.5 hours per week of care in rural communities, agency with focus on grandparents and single parent caregivers, and agency focusing on children with serious emotional disturbance.

- **Pennsylvania:** Spokesperson MaryJo Alimena Caruso, PA Respite Coalition. Pennsylvania is not currently receiving Lifespan Respite funds. However, as a result of the Lifespan Respite Advisory Committee, state maternal and child health program is funding a statewide initiative to increase number of respite options through a volunteer base in faith-based and community groups. State could use volunteers in community to train and then use those volunteers to provide free respite for others. Marketing strategy to attract new volunteers had to be softer but still informative. Prepared clear information on details and expectations, email blast and brochure resources. Once volunteer groups are funded they get training and technical assistance, checklists. Used partnership to collect data from funded programs. In last fiscal year--120,000 hours of volunteer respite service has been provided. Thirty percent of participating families had never received respite before.
- **South Carolina:** Spokesperson Anne Wolf, Lt. Governor's Office on Aging. Secured dedicated respite dollars from state legislature as a result of their State Respite Plan. Secured almost 2 million dollars in 2014, but has made lifespan respite for all ages a recurring line item in the budget starting in FY15-16. ADRC administers most of the respite vouchers, but SC Respite Coalition outreaches to marginalized populations and helps administer funds. Efforts now include increased coordination of funding.
- **Tennessee:** Spokesperson Jennifer Abernathy, TN Respite Coalition. Served more caregivers with respite voucher this year than last despite having lost their office to a fire in the fall of 2014. Coalition's board of directors conducted a strategic plan for the coalition. Evaluated four strategic priorities including growing funding streams and empowering caregiving through creative programming. Will be working with the TN Aging and Disability Commission on statewide planning for the Lifespan Respite program as well.
- **Texas:** Spokesperson Joyce Pohlman, TX Department of Aging and Disability Services. Texas spent most of year developing state plan for respite beginning with their June 2014 summit. Developed video with caregiver interviews (as of Aug 31 had not been released). Created 1-page resource page on reaching out to Hispanic caregivers; 40 percent of caregivers in TX identify as Hispanic. Testing different strategies to encourage Hispanic families to access care. Recent expansion to ADRC coverage for all counties in TX. Working to integrate caregiver support and respite into ADRCs. Monthly updates with 5-10 minute briefs on new resources.
- **Virginia:** Spokesperson Liz Havenner, VA Department for Aging and Rehabilitative Services. VA Caregiver Coalition of 150+ members. Online training program to be released in Sept/October (as adapted from Wisconsin's Respite Care Association online training resources). Supplied nearly 200 respite vouchers last year and recently released 20 new vouchers with their new federal grant.

## **Lifespan Respite Update, Kevin Foley, Administration for Community Living (ACL)**

Objective: Updates from the Administration for Community Living, a division of the Department of Health and Human Services. Overview of Department organization chart.

- Administration for Community Living
- Org. chart explanation: focus on new Administration on Disabilities, created out of the Workforce Innovation and Opportunity Act. Independent Living Administration can provide grants for care. Please get in touch with Kevin about state opportunities to pair up and collaborate with federal efforts.
  - ACL serves all across the lifespan and needs integration and collaboration to be successful
  - National Institute on Disability and Independent Living
  - Grant Specialist, Christine Ramirez, works in Office of Grant Management
  - Center for Policy Evaluations works with evaluations
  - Office of Regional Operations, 10 regions, 5 administrators
  - Center on Integrated Programs, focus on serving older adults and people with disabilities, oversees over 500 grants
  - Kevin's office: Respite is in Office of Consumer Access and Self-Determination.
- No Wrong Door System: In 2012, 8 states for funded to create a No Wrong Door system.
- 4 to 6 state grants will be given for 3-year planning of No Wrong Door system.
  - Encouragement to advocate at state level for No Wrong Door programs
- Person-centered planning enables consumers and people with disabilities to be a part of the planning process for services provided. Transportation program is working with communities to determine effective programs using community input
- Grant award to ARCH given
- 2016 ACL budget request updates. Unclear what/how much/when Congress will fund. ACL's areas of support. Funding request includes:
  - \$5.8M in care for NA population and older adults
  - ACL requests programs to make use of best practices to modernize ways of addressing needs
  - \$15M requested for Family Support Initiative
  - \$5 million requested for Lifespan Respite Program

*Discussion: Where would providers like to see program evolve? What are hopes for future directions?*

- There is competition for funding between populations that need care, so facilitating collaboration between populations and their agendas is important
- Is there a generic piece of legislation that agencies can use to draft presentation to legislatures?
  - SC found legislators who had been caregivers in their personal life which made it easier to gather their support
- State concern that funding will be eliminated. Per Kevin Foley, ACL is looking to invest and grow lifespan care in the future. Does not expect that funding will be eliminated.

- ARCH website has largest collection of resources for agencies. ACL is the smallest division of HHS.
- Office of Caregiver Services: Runs National Family Caregiver Resource program
- Messaging from federal level re: lifespan respite—what messaging is the government using? Website updates, blog, website features, Nat. Caregiver Month upcoming and featuring lifespan respite assistance. Within communication department, are looking for people willing to blog to enhance personal connection to topic. Blog writing (especially that which was published on state sites) can be sent to Kevin Foley and he will connect it for publication
- Messaging that respite is a skilled position and needs a wage increase. Ask for increase in minimum wage.
- Note on amendment and carry-over requests. (See online slides for guidelines, or ACL website).

**Peer-Led Group Discussion - Tapping into State Initiatives to Ensure Respite and Family Caregiver Support, Facilitated by Pam Catt-Oliason, Idaho Commission on Aging**

Objective: To provide a state example of embedding respite and caregiver supports into ongoing state programs and initiatives and encourage states to share their own examples of similar efforts.

- Caregiver Task Force
  - AARP funds and supports efforts of Caregiver Task force
  - Working on recommendations for a state plan
  - Has divided into work groups
- SHIP: Statewide Healthcare Innovation Plan
- Lifespan Respite Coalition (renamed Caregiver Alliance)
- Idaho has held two summits in past year. Summits enable regional outreach, local issues to be brought to the surface for discussion
- Want to create an inventory of care and resources
- Primary SHIP goals—evolve state’s healthcare delivery system to a value-based system of care that rewards improved health outcomes
- State earned grant for healthcare delivery system--\$40M over 5 years
- Movement towards patient-centered planning
- Long-term goal to reduce healthcare costs

*Discussion: How are states integrating programs/initiatives?*

- North Carolina: Attempt to build up coalition’s credibility and capacity be a go-to resource for respite referrals
  - How did NC identify state initiatives to become involved in?
  - Became involved early, partners and coalition members used their own diverse networks to determine who and where to reach out to.
- Collaborate with No Wrong Door stakeholders for support for efforts.
- Waiver programs: people attempting to use waiver programs had trouble with the terms respite vs. caregiver support.

- Ex: respite is defined as a family member leaving the home for 4 hours, but caregiver support can also be respite. Using both terms has broadened base of consumers accessing services.
- Colorado has been partnering with other states' strategies to determine best practices
- DC: Is making a large advisory group with subsets for specialization in order to tap into more people's knowledge base.
  - Trained its social workers on respite, what it is, and what options are for coverage
  - This increased buy-in and participation
- Several states have support from AARP for the CARE Act
  - Formation of task forces
- There are agencies outside department of HHS that work to support caregivers.
- Across depts.—Corporation for Nat'l and Community Services has a Senior Companion program for respite. Good option for using state offices of corporation as an available service.
- Using AmeriCorps VISTA to fund an employee is also an option for low-cost staffing.
  - Example: NH has an AmeriCorps VISTA staff member
- Increasing respite providers via workforce development: Career centers, community colleges, may be an option to increase training and awareness of job training and opportunities.
- How do we account for a lower number of providers—Baby Boomers vs number of potential providers in the millennial generation
- How do we make a 15 year plan to address issues ahead of time?
- Dept. of Labor changes on who is eligible for respite. Regulations for overtime and minimum wage are going to go into effect, after a federal court ruling.

**Respite: A Strategy for Building Protective Factors, Casandra Firman, ARCH Senior Staff**

Objective: To share information on what is the role of respite in increasing safety and wellbeing, preventing abuse. We know we all need a break, but why? There is no single, identifiable cause of maltreatment; it occurs as a result of interaction of multiple forces. Just because risk exists does not mean that abuse will occur. We can leverage protective factors, once we know the risk factors, to increase the wellbeing of caregivers and recipients.

- Risk Factors
  - Caregivers: substance abuse, depression, social isolation (significant factor), stress (evidence supports)
  - Care recipient (note—this does not mean that individuals are to blame for their own abuse. Rather, it is related to how certain characteristics of the recipient can trigger abuse): developmental disabilities, children who cannot express what they need, adults who are aggressive, acting out needs, socially isolated, substance-dependent, depression (suppresses self-care abilities and self-advocacy)
  - Relationships: history of relationship between caregiver and patient (especially with adult children as parents' caregivers)

- Community: lack of resources (i.e. respite), lack of community opportunities, perceived worth of senior citizens or people with disabilities, community norms on abuse or responses to aggression, lack of laws to support caregivers
- Economic: balance of funds between patient and caregivers
- Protocols for abuse response: what are the laws for mandated reporting of abuse of adults vs. children?
- By increasing support for respite providers we can help reduce risk factors and improve safety and wellbeing of those receiving care
- Protective factors are defined as conditions, elements, and supports which protect families and promote resilience.
- There is not much quantitative research and evidence that protective factors improve patient wellbeing
  - However, it is considered “common sense” and widely accepted from an anecdotal perspective
  - The body of research on protective factors is growing now
- The most-researched protective factors—social supports for caregivers and effects of community involvement
- Protective Factors
  - Knowledge of developmental needs & appropriate strategies for meeting them.
    - How can respite help?
    - Respite can help you understand coping mechanisms for each stage in disability
    - Enables providers with free time to learn more about coping strategies, gives free time for education and preventative care, providers can watch respite staff and learn from them
  - Pro-social communication skills: the ability to get needs met through positive communication, regulating emotions and engaging with others.
    - How can respite help with pro-social communication skills?
    - Give space to be apart, person provide respite may interpret behaviors for their meaning.
  - Nurturing and attachment: how does respite help?
    - Respite helps guide parents, modelling someone acting in a loving way towards the disabled child,
  - Concrete supports: access to tangible goods and services.
    - How does respite help? Gives time to make phone calls, do paperwork, arrange intakes, and what it takes to access other supports
  - Social isolation: respite allows the caregiver to get a break, to get companionship from trusted peers, gives people the gift of time to maintain social relationships
  - Resilience: gives adaptive skills and strategies to persevere in times of crisis. Respite provides hope and relief for caregivers.

### **ARCH Network Updates, Jill Kagan, ARCH Director**

- See slides for updates in ARCH network.
- Note Kansas public ad campaign- “Respite Refuels Families”. Ad campaign material may be permitted for use by other states
- Natural supports: programs that already exist in the community
  - How can existing programs (i.e. summer camps, exercise classes) be modified to support people with disabilities in order to provide respite?
- Conferences: Save the Date
  - October 2016 (Dates TBD) : National Respite Conference, Denver, Colorado
  - September 2016: International Respite Conference, Edinburgh, Scotland

### **National Community of Practice on Supports to the Families and the Lifetime Respite TA System: Exploring Natural Supports for Families, Mary Lee Fay, Executive Director, National Association of State Directors of Developmental Disabilities Services, Alexandria, VA**

#### Objectives:

- Goal to expand coverage and assistance for people who are eligible but not accessing services
- Goal to pay attention to ALL
- Only 13% of people with disabilities receive services outside the home.
- What is our strategy of supporting individuals with disabilities and families across the life course?
- How do we make sure that we can support the community without using the whole system (given that medical facilities don’t have the capacity to support everyone at once)?

#### *Questions, Reflections, and Discussion*

- Use of natural support has also grown partnerships and relationships with other agencies
- Person-Centered planning efforts are in a healthy tension between people who are eligible and people in the community at large, who are involved in the system.
- Appreciative inquiry and anticipatory guidance: Many of the questions we have are for non-disabled people are sometimes avoided in people who have a disability—such as: “what do you want to be when you grow up?” or “Are you wearing a helmet when you ride a bike?” Strength-based community development invites people to dream together, and treat all people with dignity and give them the same options.
- By breaking out the full community we can determine what works for people who are not in the system or not on Medicaid.
- How are you thinking of policies and practices that are integrated? What other services could be accessed?
- Anecdote: the families in the disability community often think that respite is program or an agency thing. If we change the language to be more accessible and say, “What do you need to

do to take a break?” We will get a more accurate response. That will also help people to better understand what respite options that they have.

- Website: [www.supportstofamilies.org](http://www.supportstofamilies.org)

**Peer-led Discussion Group: Lifespan Respite Grantee Role in Providing TA to Local Programs to Ensure Meaningful Outcomes and Sustainability, Facilitated by MaryJo Alimena Caruso**

Objective: What do we mean when we talk about outcomes and what is working? What is our responsibility to work with and support the grantees? What do we want from our programs and partners? How can we support implementation and sustainability in local agencies?

- Respite is often the forgotten program excluded from healthcare discussion tables. How are we going to become heard?
- Importance of visioning: what is positive and possible for agencies?
- Importance of taking a step back to think about where you want to go as a state
- What does it all mean aside from all the jargon we may be using?
- Sustainability ties together the social, economic, and community factors for each state
- What does your community really need? What is needed and demanded by them vs. what agencies guess that is needed?
  - Example of PA's development of overnight respite program when community demand was for Saturday extended day respite
- How can we support grantees to reach underserved families? How can we implement that?
- How do we break away from being solely dependent on grant funding?
  - Need to determine ways to sustain programs beyond when the funding runs out
- If we do not engage in investment, training and TA, then we aren't setting up a sustainable future
- We owe local programs more than just giving out money, we owe them support
- It is not just about bringing people to the table for funding, it is about facilitating implementation
  - Who will be helpful to have the conversation about implementation?
- Program Sustainability Framework: Various ways to support programs (see PowerPoint slide)
- The goal is to increase capacity for local programs so that we never have to turn an individual away

*Discussion*

- Strategies for planning information/collaboration/implementation support
  - Conference calls to network on different strategies
  - Local TV programming and PSAs to share information

**Respite Research Agenda from the ARCH Expert Panel on Respite Research –the Implications for Lifespan Respite, Ray Kirk, PhD, ARCH Senior Consultant**

Objective: To engage Lifespan Respite grantees and partners in the importance of respite research to their work in the field to implement and improve respite services and programming and to provide an update on the work of the Expert Panel on Respite Research.

- See slides for presented materials.

**Peer-led Discussion Group: Successful State Approaches for Measuring Lifespan Respite Outcomes, Co-facilitated by Emily Kearns, Massachusetts Lifespan Respite Coalition and Joyce Pohlman, Texas Department of Aging and Disability Services**

Objective: To discuss the role of data collection and evaluations. To show outcomes and to help people to tell their story in evaluations, to showcase successes, passion and strengths. To use evaluation as an opportunity for innovation and discovery. To show what our organizations dreams could mean down the line.

- See slides for presented materials.

*Discussion – What’s working?*

- Need funding to research correlation between caregiving, mental health, stress, depression
- Need reliable and valid measures for “stress” and other topics of study
  - University partnership can enable easier data collection
- Scale to create respite self-care goals for meaningful use of respite
  - Is required for receiving vouchers in NC
  - Who is to judge “meaningful” or “restorative” use of respite?
- PA – take the time to help people ID what meaningful activities are for them
- DC—Pre- and Post- test about coordination of care between family members
  - Scale was adapted from a CA scale
  - Contains questions regarding mental health of caregivers being served
- Kirk, PhD—what is the value of the information being gathered? Do you have the capacity to work with the data that you are collecting?
  - Goal is to gather the best data with the least questions
  - You could also look at body language when people are answering questions. What are people saying so that they can receive funds, and is it accurate?
    - PA—has addressed that problem by allowing funding to anyone regardless of answers to questions