State Grantee/Coalition Report Outs: Ideas for Sustainability and Major Accomplishments

Kerrie Reidelbach (MT grantee):
- Monthly meeting with partners throughout the state. Every other month, face-to-face, others are web meetings. If a partner does not attend, one of the attendees contacts the absent member to get them up to date. Executive Committee charged with bringing in new members.
- Undertaking strategic planning with a facilitator.
- Educating staff at ADRC on responding to respite requests.

Vicki Clear (MT Coalition): DEAP Respite program for 15 years. Money has been pieced together and still going.

Linda Porter, Easter Seals (WA Respite Coalition): 2002 Respite and Crisis Care Coalition formed. State received 2013 expansion grant. Learning a lot about voucher systems. Will be tapping others who do vouchers. We also had a “purpose to practice” session recently which led to a strategic planning meeting with a pro-bono facilitator. Plan this year is to work on sustainability.

Dana Allard-Webb (WA grantees): Implementing T-Care.

Elizabeth Harris (AZ grantee and coalition rep): 5th summit this year on Respite. Respite vouchers using title 3 dollars will be available this year. Respite registry in conjunction with Rewarding Work rolling out in November. Caregiver coalition hoping to become a nonprofit. Worried about sustainability & may need a fiduciary agent when non-profit.

Terri Wilson (NJ grantee) and Eric Joice, Jessica Goldsmith Barzilay (NJ Lifespan Respite Coalition). The coalition chair reported they’re working on sustainability. Concentrating on awareness building. They have 800 responses to a caregiver survey for their frequently used website for people seeking respite and have some preliminary data. Collaborating with University Center on Excellence to provide respite training. UCEDD is already working on workforce development. Working within a state system that is in a great deal of flux. Found out where people were going to find respite and instead of creating their own website, help existing websites to have information on Lifespan respite.

Meghan Baskett, Lynn Robinson and Val Saiz (CO Respite Coalition) and Peggy Spaulding (CO Grantee): Re-launched website which is now in its 3rd year. It now has a provider directory. In process of doing regional summits and developing coalitions across the state. Coalition is now recognized across the state. On sustainability, legislation was passed. Surcharges for crimes against disabled persons go to respite. They’re educating judges and DAs. To further sustain the program, the State put $150,000 line item for respite for non-profits to provide respite. Money is going to programs.

MaryJo Alimena Caruso (PA Respite Coalition): Working as a coalition for 15 years. Having an MOU with the state as part of the Lifespan Respite grant helped get us to the table. Getting
ready to launch a website. We are handing out vouchers with an evaluation component which helps us keep track of usage and dose and to measure reduction of stress. Last week of Sept. is respite awareness week. A 72 yr. old woman brought her 96 yr. old mother to the celebration and she received respite for the first time this year. Working to identify an unmet need among people who don’t know what respite is.

Pam Catt-Oliason (ID grantee): First year of grant. Long-term volunteer day center this year and a Senior companion program. They also have an Alzheimer’s Supportive Services Grant. Faith in Action → Friends in Action, These efforts provide hope for sustainability.

Kathy McKeon, Archdiocese of RI (RI partner): Faith-based group. Lifespan Grant is creating a bridge between the state and the Archdiocese. This year, put Lifespan Respite funds directly into services. Seeing a significant reduction in respite dollars because of sequestration. There is a significant wait list for respite. Their 1115 waiver was renewed with services to begin again in January and respite is back in as an allowable service. They’re trying to work collaboratively with other groups in the state. Implementing Powerful Tools for Caregivers. Lt. Governor developed a state Alzheimer’s plan – partners helped get respite into the plan. Hopeful that networking will result in sustainability. They plan to present Rep. Langevin an award for his championing of Lifespan Respite.

Joan Rafferty (MA Coalition) and Amy Nazaire (MA grantee): Accomplishments: pulling off the national conference! MA awarded an integration & sustainability grant this year. With an expansion grant they received last year, awarded 10 mini-grants for the underserved population. They built an evaluation component into their grant and will host a summit for their grantees in November. They were just selected by ARCH to work with the Finance Project on sustainability. Website up since Feb. raising level of awareness in State. Will be having a family caregiver conference in the Spring. Partnership with universities will help train 100 respite volunteers across the state.

Kathy Mayfield Smith and Susan Robinson (SC Coalition): Collaborations with agencies that serve children (Family Connections is their federally funded Family to Family Health Information Center) and ADRC that serves adults. Coalition has been in existence since 1999. The coalition is a private non-profit. Along with state grantees in Lt Governor’s Office on Aging, developed state respite plan and presented it to the legislature. New Lieutenant Gov. went on a tour of respite programs and advocated for a $3 million one-time state grant. Developed a voucher program. Getting the word about respite statewide. Re-developing their website. Developing regional advisory committees across state to help streamline access to respite. SC is moving to a managed care model, state wide. Trying to inspire churches. Looking for seed-grants. Benevolence policy to assist churches to make respite funds available to families. Counting on the faith community to help with sustainability. Check the coalition website.

Sharon Kaiser (NH grantee): Received a no-cost extension this year and developed a strategic plan with stakeholders. Hoping that the strategic plan would suggest a structure for the state respite coalition development. Finally have cochairs for the coalition. Grant activities included developing a platform for training for respite providers using on-line modules and getting trained providers on a web-based registry so people can find respite providers. Working with Rewarding Work to develop online registry.

Tammi LeBlanc (LA grantee) and Crystal Smith (LA Coalition): Problems in the first years. Had a respite summit and developed a plan including sustainability. Did not get a sustainability grant but decided to go ahead with the activities. “LA Answers”
William Abernathy (DE grantee): Got a new grant--biggest accomplishment.

Alicia Blater and Linda Kendall Fields (NC grantee): Used expansion funds to issue RFAs. Some surveys developed to capture data about effectiveness of new services. Tools available on ARCH website. Developed a rigorous reporting process for local programs. "Money follows the Person" gets an enhanced federal match and we have used these funds to help support sustainability. *Making Connections* are e-learning modules in development to train social and medical service providers and options counselors to help families access respite.

Lois Scheaffer-Kramer (IL Coalition): 2009 grantee, emergency respite program served 108 families first year. It is still functioning with limited funds. They have small pots of money to keep emergency respite funded. The Coalition is funded through the Dept of Children and Family Services and they put some of these funds into emergency respite. Successful in getting state leaders to talk with each other. The coalition is in transition and they are in process of hiring a new coalition state-wide coordinator. They want to increase the membership of the coalition. They're training volunteers throughout the state to provide respite. With managed care coming into the state, the developmental disability agency wants to revamp respite.

Jennifer Abernathy (TN Respite Coalition): State department on mental health has supported respite services since 1988. They support respite for families of children with severe emotional difficulties. TN respite coalition - 10th year as a non-profit. Received a grant to develop a database to track providers. Able to pull good numbers--who is getting vouchers, how they are using funds. Creative advertising firm is going to redesign their website (free) in a ‘create-a-thon.’ Is seeking support from a large charitable foundation in TN as part of their sustainability plan. There are pockets in the state that are a challenge & they'll focus on them in the future.

Al Ruble (OK grantee): Able to help individuals who were previously ineligible for respite. The respite coalition, the Oklahoma Respite Resource Network (ORRN), was developed in the 1990s. In April held a large meeting with as many stakeholders as possible to strengthen the coalition. ORRN meets monthly. Using Lifespan Respite grant funds, they set up mobile respite with a small van going from town to town and awarded 7 mini grants. All but one will be sustainable. As the new lead on the grant, he is still on a learning curve.

Vicki Kemp (NV grantee): All lifespan respite resources are on a web-portal. Training modules. Direct-service funding available. Still looking for sustainability funding.

Sharon Johnson (NE grantee): Established a crisis respite policy and program. Sustainability with state funds.

Jane Byrnes (OH grantee) and Pat Luchkowsky (OH Respite Coalition): Biggest accomplishment, involvement with Medicaid managed care programs in OH. Using a common tool in state for caregivers, everyone going into managed care will be assessed for respite. Imbedding respite into all systems including managed care. That's the sustainability plan. Mini-grants for volunteer respite programs using a set of respite models so that anyone who wants to start a program will have a model to use.

Ellen Nau (VA grantee): Major accomplishment: Involvement and expansion of caregiver coalition. Used expansion grant to offer one time vouchers to families. The voucher program was highly successful and will be looking for additional state funding to sustain the effort. Great volunteers keep the coalition going.
Java Bennett (AL Coalition): Finishing 2nd federal grant. Hope to still be in existence. Accomplished a state respite law in the state they hope will be funded. Developing a state strategic plan and expanded their voucher program. Developed a Sharing the Care toolkit for local group development and will share the care toolkit with faith-based organizations.

Gina Ervay (KS Coalition): Accomplishment: training and credential programs that can lead to an Associate's degree in partnership with community colleges. Pulling in new partners.

Ann Marie Cook (NY Coalition): Caregiving listening sessions (11 in state) held and will be issuing a report in a few weeks. Having two respite conferences this year. Web-site will be connected to the ADRC. Getting coalition partners to help with sustainability.

Jeanne Yordi (IA grantee) and Mazie Johnson (IA Coalition): Expanded emergency care program. In 2nd year of 1st grant. looking at training requirements in the state through a survey. Fourteen regional summits throughout the state. Trying to re-vamp the coalition from a focus on children to a lifespan approach. Will do a strategic plan in November.

Heather Chun (HI grantee): Pulled in partners from around the state. Huge support from legislators. Passed resolution in state legislature to explore TimeBanking for volunteer respite. Have a huge informal network in HI and relying on natural supports to help provide respite. Going through strategic planning for the aging network and will incorporate respite into that process. Wrote a grant to get two Vista workers this year and bringing on 3 more to help.

Joyce Pohlman (TX grantee): Doubling the number of ADRCs in state. Getting involved n the Balancing Incentives Program. Operational manual for Options Counseling will include caregiver and respite awareness with their input. Sustainability grant will focus on faith-based respite. Engaged in major outreach to faith community to get them to buy into respite.

Jim Schroeder (WI Coalition): State Lifespan Respite program since 1999. With Lifespan Respite grant, have focused on training respite providers, respite 101. They have 700 respite care workers and posting them on a developing respite registry. Maintaining ongoing state support.

Peer Led Discussions

1) Tennessee Voucher Program – Jennifer Abernathy, TN Respite Coalition

Coalition administers $ 179,343 in voucher funds for ____ hours of respite for just under # families. Voucher funds come from Dept. of Mental Health, Parkinson’s Foundation, Community Foundation of Middle TN and other pockets of money. Some are restricted by age or geographic area.

Packets are given to caregivers. Require signed copies of how you’ll use respite, who you are using as a provider. There is a free registry check.

The provider documents what they did; the caregiver documents what they did with their respite time. The funds need to be used in a timely manner.
Questions came up immediately about family responsibilities for paying worker’s compensation and employee payroll taxes. If you keep vouchers under $600 per year, this is not an issue.

NE commented that they pay the caregiver and the caregiver pays the provider – that way there are no federal restrictions.

Discussion: re: payments to providers & meeting compliance with the IRS 1099 vs 1098 forms

ARCH directed individuals to the National Resource Center on Participant Direction and the Guidebook they prepared for ARCH on participant directed respite and voucher programs.

Discussed the need for a Fiscal Intermediary or other Financial management services to alleviate issues around IRS tax issues, employment status, and worker’s comp. These Admin costs associated with a voucher program could overwhelm the effort.

Is there a checklist to help individuals in hiring respite workers, especially about responsibility around tax issues? Suggested Independent Living – IRLU resource

TN's Caregiver evaluation for their voucher program.
  Out by mail
  Use pieces of the ARCH evaluation tool
  Decent (20-50%) return rate
  Timing of sending out the survey is important
  Do reminder calls

How long is the process? How does it impact emergencies?
  Must show proof of income & proof of diagnosis
  It can be a quick turnaround if it fits with the funding source

See ARCH website for updated TN Voucher Tools.

2) Recruiting and Training Respite Providers - Gina Ervay, KS Lifespan Respite Coalition and Sharon Kaiser, NH Lifespan Respite Project

KS Lifespan Respite program focused on training providers – offering college credits – developing relationship with community colleges; Certification available as part of workforce development. Partnered with Money Follows the Person Program to seek and secure additional training and TA support for workforce development from CMS’s National Resource Center on the Direct Service Workforce.

NH also has a training program & a tiered curriculum. The grantee agency, Special Medical Services for Children partnered with the Bureau of Elderly and Adult Services and switched from original curriculum developed with the College of Direct Support to Relias/Learning to be used across all programs. Respite provider curriculum provided to grantees/partners for review. Trained providers will be listed on a new registry being developed by Rewarding Work with additional partners. See ARCH website for tools.

Ohio – involved with statewide direct service training initiative & also a career path for respite providers
CO – camp counselors get college credit
    Adoption Exchange is paid to do training for the coalition
    9 nursing schools – nurses are required to go through the program; that’s free to
    Coalition or cost-neutral (pediatric rotations)

3) **Faith-based Respite Initiatives – MaryJo Alimena Caruso, PA Respite Coalition**

Statewide effort to engage faith community in providing respite grew out of partnerships
resulting from the Lifespan Respite grant. Children with Special Health Care Needs providing
$750,000 over three years to provide training and TA to the faith-community to engage in
respite support and services.

A fidelity check list - owned by the state DOH

Dealing with liability issues to keep both children and providers safe
Small mini grants going to 501(c) 3 agencies.
May consider asking for a match
Definition of a volunteer – “time is freely given”