

Bring, Brag, and Borrow Session***State Updates on Lifespan Respite Grant and Coalition Activities*****Lifespan Respite Grantee and Partner Learning Symposium****September 23, 2016****Denver, CO****Alabama**

- Alabama Lifespan Respite Resource Network is developing a caregiver simulation similar to existing poverty simulation. The goal of the simulation is to enlighten the public on the stressors and hardships that the average family caregiver experiences daily. University students will participate in the caregiver simulation for numerous trial-runs and then the simulation will be open to the public.
- Alabama Lifespan Respite Resource Network conducts training on natural respite resources, preventing caregiver stress and burnout, and a variety of other topics. Caregivers who attend these training receive a respite voucher.

Arizona

- In 2006, Arizona passed state legislation and provided \$500,000 in state funds for Lifespan Respite. The program subsequently lost those funds during the 2008 financial downturn.
- In 2009, a federal Lifespan Respite grant was secured to support building a coalition that became, one year ago, a non-profit entity.
- Three months ago, the state dedicated funds from its Dementia Capability grant to support the AZ Caregiver Coalition. During the past ten years, the State was successful in securing five federal grants that were conceptually connected and function in unison, and that allowed Arizona to build upon earlier foundational grant projects in a coherent way.
- The Governor will participate in planned National Family Caregiver Month activities in November.
- In partnership with Arizona's Alzheimer's Association, the coalition will launch a public information campaign that is the culmination of 10-years' work.
- More information about Arizona's caregiver resource line, managed by volunteers who have been trained by the coalition, and the \$300 vouchers for respite care that are available to family caregivers, can be found on the coalition website: <http://www.azcaregiver.org/>

Arkansas

- The second Lifespan Respite Awareness Day was held at the Arkansas State Capitol, and a proclamation was signed by the state's governor. As part of Lifespan Respite Awareness Day, the first Outstanding Service Award was given.
- Arkansas continues to engage in marketing and adding to its website.
- Their current major area of emphasis is on caregiver training. In partnership with UAMS Schmieding Home Caregiver Training, they hosted REST training, which 9 new trainers received. This year, 4-hour sessions will also be offered. The sessions are advertised and held on multiple dates to increase attendance. Participant evaluations have been positive.
- In October, a second summit to support the development of faith-based respite programs will be held. At the summit, a neuropsychologist will speak on the importance of respite for caregivers' health.

Colorado

- CO Lifespan Respite awarded mini-grants to community agencies to help sustain their respite activities
- Colorado is focusing on their respite voucher program for care recipients of all ages, in all areas of need and their caregivers.
- Colorado recently provided a respite weekend at a camp in a beautiful mountain setting, at which they provided care for children of the family caregivers.
- Colorado's Respite Task Force is comprised of 14 people appointed by state agencies in accordance with state legislation. The task force studied issues related to lifespan respite and made recommendations in the following areas: 1) Conducting a cost-benefit lifespan respite study; 2) Building a statewide training inventory to build a respite workforce; 3) Conducting outreach and awareness activities; and 4) Streamlining systems and reducing duplications and confusion. The Task Force recommendations were submitted to the state legislature in January. In response, the state is investing \$900,000 to implement the recommendations.
- With the new grant award, the CO program will focus on respite for kinship providers.

Delaware

- Delaware is in year three of their Lifespan Respite Grant and will use new grant award to provide respite vouchers to individuals on their waiting list.
- Two years ago, the DE Division of Developmental Disabilities Services (DDDS) asked the DE Lifespan Respite Network to subcontract and manage the grant.

- Delaware Lifespan Respite Network is engaged in a Relative Respite grant project aimed at supporting grandparent caregivers 55 years-of-age or older and other family caregivers.
- DE Lifespan Respite Network has 500 family caregivers (who choose their own provider) on their voucher caseload with one person managing all cases. The state is working on selecting a computer program to help them efficiently manage vouchers for those families.

Florida

- Florida's Lifespan Respite Alliance exists as a non-profit, stand-alone entity working in partnership with the state's Department of Aging. Together they are doing foundational work--building a website; building alliances; building regional hubs responsive to regional differences.
- Florida called attention to their website blog that includes a collection of stories from caregivers. The goal of the blog is to normalize respite from caregivers' perspectives.
- Florida also reported that one of their board members is president of the American Association of Caregiving Youth, an often overlooked population.

Idaho

- Idaho's Lifespan Respite Coalition has become the Idaho Caregiver Alliance. The Alliance strives for diverse membership. Their focus is on working toward sustainability.
- In 2014, the state passed a Concurrent Resolution to create a task force that issued a 2015 report to state legislature and to the state health care committee. The report focused on respite caregiver issues, and resulted in the development of an Idaho Caregiver Action Plan that aims to educate others about the lifespan respite sustainability plan.
- In October 2016, the Idaho Caregiver Alliance in partnership with Parents Unlimited, a group that represents parents of children with disabilities will, cosponsor the ID Caregiver Conference.

Illinois

- Illinois does not currently have a Lifespan Respite grant. The Illinois Lifespan Respite Coalition is working with a state agency to apply for the grant again.
- The Coalition received \$24,000 in emergency respite funding from the Department of Children and Family Services (DCFS) last summer, and recently received an award letter from DHS in the amount of \$150,000 for emergency respite.

- The Illinois Lifespan Respite Coalition website, which they continue to develop, had over 10,000 hits by the end of June, 2016.

Iowa

- The Iowa Respite Coalition continues working on engagement and visioning through strategic planning. They are working towards nonprofit status.
- They held a caregiver conference last year. Jill was one of the keynotes. The State is moving to Medicaid managed care and this was an issue of central concern to conference participants and continues to be a significant issue in IA.
- Another conference will be held this year with AARP.
- The Coalition is working on developing a new website, but it has been challenging to get approval from the state.
- The ADRC searchable data base is up and running.

Maryland

- MD received its first Lifespan Respite grant this year. More than 30 committed partners in the grant will meet on October 18 with the Secretary of the MD Department of Human Resources.
- MD has a strong infrastructure for family caregivers through the MD Caregivers Support Coordinating Council that was established by statute in 2001. Four state agencies are mandated to appoint a representative to the Council. Also on the council are respite provider agencies and family caregivers.
- The Council did a survey in 2015. 2400 family caregivers participated and 1800 fully completed the survey. Respite was the #1 request.
- MD has state funding for respite.
- MD is having a statewide event on Nov 3. The First Lady of MD, who is a family caregiver, may participate.
- MD expressed a need for help with their website.

Massachusetts

- The MA Lifespan Respite Coalition hosts a cable television show with monthly tapings on a variety of topics including respite, exploring spirituality in relation to caregiving, etc. The show can be viewed on YouTube. Anyone in MA can request it through their cable network. They showed a short video to Learning Symposium participants that presented a montage of clips from the cable show.

- With their new grant, MA will initiate a third round of mini-grants to community based organizations with a focus on providing respite to culturally diverse groups. The effort will be evaluated.

Montana

- The Montana Lifespan Respite (LSR) Coalition, in collaboration with the Department of Public Health and Human Services (DPHHS), hosted a Lifespan Respite Summit in March. The Summit was titled: *Riding the respite Wave: Sustaining the Momentum*.
- Currently, MT has a respite voucher program that reimburses family caregivers for respite. By the end of the first year, 116 vouchers had been awarded with 50 people on a waiting list. The oldest caregiver is 91 and the oldest care recipient is 102. A significant portion of funding is used for respite for children. The program relies on 60 referral sources from various agencies across the state. The program utilizes cost sharing based on income and related expenses. They are able to use the amount that families contribute to the cost of respite as in-kind match. Family caregivers in 30 counties have received vouchers. The new grant will be used to reach families in more isolated counties that have not yet been served.
- On the issue of sustainability, the coalition chair meets with Governor's office staff, the Alzheimer's Association and others. They are working on securing respite funding in the Governor's budget. The Governor is a lifespan respite supporter as he appreciates how much they have accomplished with so little.
- With their new grant award, MT will be focusing on working with the faith community to expand respite and caregiver support.

Nebraska

- Nebraska undertook a statewide strategic marketing plan and engaged a professional marketer to review all local marketing strategies, including use of Facebook. The goal is to clarify the message by tag lines, uniform fonts, consistent colors and logos used by each regional network within the Nebraska Lifespan Respite system. The primary audience for the new marketing strategy includes caregivers, providers, advocates, and employers. An evaluation plan is in place to assess the value of the marketing strategy.

Nevada

- The grantee is overseeing a marketing and awareness campaign and working with a vendor to roll out the campaign.
- BRI Care Consultation they began with their last grant is now being sustained through the ADRCs.

- The grant funded vouchers in the past. The NV Lifespan respite program does not receive support from state legislators as has occurred in other states to sustain the effort.
- Training for respite providers has been lacking. They are now planning to have REST training available across the state and would like to sustain this long-term.

New York

- Main objective is REST training. The Office on Aging will put additional funds behind training.
- The NYS Caregiving and Respite Coalition is hosting a statewide conference in November. Jill will keynote on volunteer respite initiatives.
- The Lifespan Respite grant has funded mini grants on volunteer efforts, including a faith-based effort in the Finger Lakes region.

North Carolina

- One group in the NC Respite Care Coalition put together material on utilizing the faith community for respite. Pamphlet was disseminated to the group on sharing table (posted on the ARCH website).
- In their Lifespan Respite voucher program, they distribute a form that allows family caregivers to plan how they will spend their respite time and to identify their personal goals for respite. They evaluated this initiative with a control group of family caregivers who did not use the respite planning form. There was a statistically significant difference in stress reduction between those who used the planning sheet and those who did not.
- Their caregiver-directed voucher program is administered by the North Carolina Respite Care Coalition and this year the grant was able to support this effort with some administrative funds awarded to the Coalition.
- The new grant award will allow NC to triple current funds for the voucher program to serve the unserved. They want to serve more children, individuals with traumatic brain injury, and veterans.

Pennsylvania

- The TakeFive statewide respite volunteer initiative for children was an outgrowth of the PA Lifespan Respite Advisory Committee. The state Maternal and Child Health Program funded it to build community and faith based respite initiatives across the state. Key to this effort was the provision of technical assistance on implementation and fidelity from a statewide coordinator. They are wrapping up the initiative that was evaluated. They trained 25 community based agencies and churches to enhance respite services. 720,000 hours of

volunteer respite valued at \$16.3 million was provided. They trained individuals to be master trainers with a training curricula that can be adapted to communities. Results have been shared with a variety of agencies.

- A new crisis nursery is now running a full scale. They are collecting outcome data on effectiveness.
- A Respite Awareness Week was held in early September. Legislators sent in messages of support and pledged to support respite.

South Carolina

- The South Carolina Respite Coalition was started in 2001. The Lifespan Respite grant is administered by the Lt. Governor's Office on Aging in collaboration with the Coalition. Networking has been paying off. They now have almost \$3 million from the state legislature for respite, with \$2 million being used for the aging population through vouchers. Some funding used for other populations.
- Formed a bridge group to work with Alzheimer's Association and the SC Institute of Medicine and Public Health which issued a report with recommendations for a statewide sustainable long term care plan. One recommendation was to "improve access and funding for flexible respite services." Following the release of the report, IMPH formed an Implementation Leadership Council of key stakeholders to prioritize the recommendations and guide implementation. Businesses, employers, caregivers are involved. Report can be found at <http://imph.org>.
- Coalition involved in planning group to use Medicaid for treating mental health issues.

Tennessee

- In the most recently reported year, the TN Respite Coalition served over 350 caregivers with 2,000 hrs of respite through their voucher program using 8 different funding sources. They received over 1000 calls to the HelpLine.
- TRC provides respite through its Senior Companions Program. Through Senior Companions, TRC is starting a pilot project in Music and Memory for people with any disability. Customized playlists will be used to improve behaviors.
- TRC currently uses a tool to help caregivers plan their respite time. They are developing an online portal so caregivers can enter their data online.

Texas

- A major reorganization of state agencies has occurred in TX that will impact respite. The state has required that all associated entities exist as Advisory

Committees rather than coalitions. The TX Respite Coalition is now the Lifespan Respite Advisory Committee.

- Texas completed a comprehensive strategic plan in the last year. With the help of the newly formed Lifespan Respite Advisory Committee, they will be using the strategic plan to operationalize activities and to determine how to distribute funds equitably across the state.

Virginia

- Virginia continues to implement its respite voucher program. Last year 227 families receive respite vouchers. This year 210 families received vouchers. They have a waiting list of 116 families. The vouchers are completely federally funded with Lifespan Respite funds. The voucher program has consumed a lot of the grantee's time and help will now be provided in voucher administration to ease the burden.
- The VA Caregiver Coalition is trying to write a bill to establish a Caregiver Task Force and engaging in advocacy to educate state legislators to support the voucher program.
- The coalition and the grantee developed and launched online training for respite providers.

Washington

- Lifespan Respite Washington developed a Memorandum of Understanding with the state's Children with Special Health Care Needs Program to provide respite vouchers to this population. They hope to be able to replicate this pilot.
- With their new grant award, WA will be working with Native Tribes to develop culturally responsive respite.