

Lifespan Respite Track and ARCH Presentations At the National Lifespan Respite Conference

Tuesday, June 22, 2021

1:00 – 2:10 PM CT Breakout Session A

Moving Respite Forward in New York State

Doris Green¹, Abbey Lavazzo and Deana Prest²

¹New York State Caregiving and Respite Coalition managed by Lifespan of Rochester, ²New York State Office for the Aging, Division of Policy, Planning, Program and Outcomes

Through presentation materials and interactive activities, participants will learn about core components used for Lifespan Respite in New York State to build capacity, engage partners, and undertake ongoing sustainability planning and implementation. Presenters will share information about our history, structure, and growth as a Lifespan Respite state grantee from 2010 to present.

Presenters will discuss use of the ARCH Sustainability Toolkit for Lifespan Respite action planning and implementation to help move respite forward, focusing on two of the New York State Caregiving and Respite Coalition (NYSCRC) services important to its sustainability: (1) The NYSCRC Caregiver Simulation, and (2) NYSCRC in its role as the national point of contact for Respite Education and Support Tools (REST) Master Training. As part of its Lifespan Respite model, presenters will share information about how the New York State Office for the Aging (NYSOFA) is implementing the NY Connects No Wrong Door system for access to long-term services and supports across the state, including access to its public NY Connects Resource Directory and its respite listings. New York also is expanding efforts to focus on caregivers in the workplace and will provide information on the tools being developed for caregivers and employers, including use of the University of Wisconsin Caregiver Survey as part of this effort.

2:15 – 2:50 PM CT Breakout Session C

Partnerships for Caregivers in a No Wrong Door/ADRC Environment During a Pandemic

Jessalyn Bridges and Alicia Hess Blater

North Carolina Division of Aging and Adult Services

We often hear, “I wish I had known about your service earlier” or “Why didn’t anyone tell me about you?” How can you equip staff outside your organization to share information about your services, and maybe even sign them up to receive those services? Come to this presentation to hear about how North Carolina partnered with their United Way 2-1-1 Call Center Staff and other organizations who interact

with family caregivers seeking services to increase referrals to local respite services and the state's Lifespan Respite Voucher Program.

We'll also discuss methods for finding and building local referral partnerships that could be great at sharing your message if only they knew who you were and what you did.

2:55 – 3:30 PM CT Breakout Session C

Lifespan Respite in Adult Day Health Centers - Successes and Challenges

Jutta Ulrich¹ and **Brandon Baxter**²

¹Arizona Caregiver Coalition and ²Nacog Area Agency on Aging, AZ, USA

The Arizona Caregiver Coalition works with the Arizona Department of Economic Security to administer the Lifespan Respite grant. Arizona chose to apply funds to respite provided in adult day health centers (ADHC) and added a voucher for in-home respite in the third year of the grant. This presentation will review the challenges in working with the adult day health centers as well as the positive outcomes for the family caregivers.

The presenter will share their reasons for choosing to work with adult day health centers initially, the benefits of ADHCs for family caregivers, as well as the concerns and barriers arising from use of ADHCs. The limitations of the day centers helped highlight some of the shortcomings of the respite network: lack of overnight respite, centers for younger people, respite for families caring for a person with behavioral health issues, and evening or weekend respite for caregivers who are working. The analysis of demographic data also indicates that additional care must be taken to serve individuals other than caregivers of older adults and to serve sub-populations such as Hispanic and Native American families.

Wednesday, June 23, 2021

1:30 – 1:55 PM CT Breakout Session D

Advancing Respite Research - Findings from the 2020 Respite Research Summit

Ray Kirk, PhD

ARCH National Respite Network and Resource Center

On September 29-30, 2020, ARCH convened the virtual Respite Research Summit attended by more than 130 national and international participants including researchers, foundation and government representatives, policy analysts, advocates, Lifespan Respite grantees, partners, and providers. The

Summit was part of an ongoing initiative by ARCH to advance a respite research agenda developed by an Expert Panel previously convened by ARCH.

The Summit provided an opportunity to assess progress made in advancing the Expert Panel's respite research agenda and a forum for participants to recommend next steps. The results of the Summit will inform the Committee on Advancement of Respite Research (CARR), a committee of experts convened by ARCH to assist with the ongoing agenda to build an evidence base for respite. Session attendees will become knowledgeable about the status of respite research, ARCH's continuing efforts and activities to strengthen the evidence-base for respite, and findings from the Summit that will inform the work of ARCH and the CARR moving forward to advance and strengthen respite services.

1:30 – 1:55 PM CT Breakout Session D

Collaboration at a national level to research, develop, and pilot a National Respite Provider Core Training Curriculum and Recruitment Campaign

Lisa Schneider¹ and Kim Whitmore²

¹Respite Care Association of Wisconsin, ²Marquette University, Milwaukee, WI

In this session you will learn how and why a collaboration at the State and National level are to develop, test and scale a respite workforce recruitment, training and retention program to better meet the respite needs of families, particularly in light of the impact of the COVID-19 pandemic on the workforce.

The project is managed by the ARCH National Respite Network and Resource Center in collaboration with the National Academy for State Health Policy under a Lifespan Respite special project grant. The Respite Care Association of Wisconsin (RCAW), in collaboration with an evaluation consultant with Marquette University, will lead the activities to build upon RCAW's *Respite Care Certificate Program* (RCCP). RCAW's respite provider training curriculum will be enhanced to meet respite-specific core competencies developed by an Expert Work Group and then field tested in up to 10 states.

The focus of this session will be on the power of collaboration at multiple levels, i.e., local, state, and national. The goal of this collaborative project is to help states increase the number of qualified and well-trained respite care workers, improve respite provider recruitment and retention, and, ultimately, improve the quality of respite care and better meet the needs of culturally diverse, urban, suburban, rural, or frontier families across the nation.

Presenters will then announce the application process and criteria for the selection of States that may be interested in piloting this project for 1 year.

1:30 – 2:45 PM CT Breakout Session D

Models of Exemplary and Innovative Practices in Lifespan Respite Care/Short Break Programs in the U.S.

Susan Summers, Casandra Firman¹ and Barb Williams²

¹*ARCH National Respite Network and Resource Center* and ²*Iowa ChildServe Respite*

ARCH National Respite Network and Resource Center solicits applications for respite/short break programs and services across the United States to identify models of Exemplary and Innovative respite practices. Because caregivers rate respite/short break services as among their highest priority, it is important that respite/short break programs and services are guided by evidence of their merit. In the process of selecting honored respite/short break programs and services, ARCH interviews program leaders to learn how their programs ensure excellence in day-to-day practice, document positive outcomes accruing to caregivers and care recipients, and sustain services into the future.

Programs designated by ARCH as innovative and exemplary vary in mission, funding sources and levels, service goals and approaches, and populations served. All innovative and exemplary programs selected, however, demonstrate conscientious use of approaches supported by research or program evaluation evidence and shown to benefit care providers and care recipients.

In this presentation, we will describe the 7 qualities and characteristics of programs and services that make them exemplary or innovative; highlight how one program designated by ARCH as Innovative and Exemplary applies these criteria in their day-to-day practice; and provide real-life examples and commonly used strategies for bringing excellence to respite/short break programs and services no matter the program size, location or funding level.

1:30 – 2:45 PM CT Breakout Session D

Innovative Strategies for Working Across State Programs Providing Respite Services in Massachusetts

Leanne Winchester¹ and Amy Nazaire²

¹*University of Massachusetts Medical School - Commonwealth Medicine* and

²*Massachusetts Department of Developmental of Services, Northeast Region*

Family caregivers provide critical supports to care recipients across the lifespan. Respite can benefit caregivers who are burdened by the challenges they face in this role. However, long term services and supports provided by state agencies primarily focus on the needs of care recipients. This presentation will describe how the Massachusetts Lifespan Respite Program, through an Advanced Lifespan Respite Grant, leveraged the experience and expertise across state agencies and community partners in a strategic way to increase the capacity to serve individuals eligible for state agency services and the wider

constituency of caregivers who would benefit from respite. Presenters will engage attendees in discussion of collaboration theory and the rubric used to measure collaboration, as well as the process collaborators used to define a common vision.

2:55 – 3:30 PM CT Breakout Session F

Creating Respite Where It Doesn't Exist: A "Gap-Filling" Person-Centered Approach to Respite

Cheryl Dinnell¹ and Jamie Ahumada²

¹Nevada Lifespan Respite Care Coalition, ²Nevada Aging and Disability Services Division

Through a pilot program funded by the Administration for Community Living's Lifespan Respite Care Program, we will share what it takes to provide respite to unserved & underserved populations across the lifespan of caregivers.

Nevada's Lifespan Respite Rx pilot program is a "self-directed" service model that incorporated a person-centered approach, using the MyLifeCourse Respite portfolio, specifically for caregivers who do not meet eligibility criteria of other programs. Caregivers determined the design and delivery of the respite service, while the program not only funds respite but helps a caregiver "create respite where it doesn't exist" by providing support not typically found in other respite programs. The goal was for caregivers to use respite regularly for one full year. Respite Rx was the prescription; 2-4 hours per week was the recommended dosage.

Respite Rx provides valuable insight at the program level to the supportive direct services that caregivers are looking for and what Nevada has learned to better serve caregivers. Attendees will get to see how the MyLifeCourse Respite Portfolio tool and other supports helped tailor respite to the caregiver and care recipient's needs.

Thursday, June 24, 2021

11:00 – 12:15 PM CT Breakout Session G

Lessons Lifespan Respite Washington Learned from Collaborating with Diverse Groups of Caregivers Prior to and Mid-Pandemic

Dana Allard-Webb, Geene Delaplane, Rosalyn Alber¹, and Tracy Kahlo²

¹Aging & Long-Term Support Administration, Washington State Department of Social and Health Services, ²Lifespan Respite Washington and PAVE|Partnerships for Action, Voices for Empowerment

This presentation will walk through a history of trial, error and evolution in working with Tribes and other distinct communities like caregivers of people with developmental and intellectual disabilities and

caregivers of people with traumatic brain Injury. We will share our journey of reinvention and collaboration, prior to and mid pandemic. Washington has been challenged to provide culturally relevant outreach and services to Native American Tribes. Lifespan Respite Washington also experienced resistance in another unique population; caregivers of people who have a traumatic brain injury. We will present an overview of our journey with these caregivers who share a reluctance in using respite services.

We will take advantage of group knowledge among participants during our presentation. Attendees will be asked to share in the conversation, ask questions and explore best practices and ideas to move respite services forward for underserved populations and expansion to other populations that are challenged in using mainstream programming.

11:30 AM – 12:45 PM CT Breakout Session H

The Cost of Moving Forward: Calculating the cost of short break/respite services

Cassandra Firman¹, MaryJo Alimena Caruso² and Catherine Shanahan³

¹ARCH National Respite Network and Resource Center, USA, ²FRIENDS National Resource Center for Community-Based Child Abuse Prevention, USA, ³Family Respite Services, Ontario, Canada

We know that short breaks and respite are beneficial to families caring for a loved one with special needs, but do we know how much it really costs in dollars and cents (or pounds and pence, euros and cents, or the currency of your choice?) Respite programs may be a sound investment in the health and well-being of individuals with special needs, their families, and the larger community, but the actual cost to deliver services is not always clear. For greater accountability to funders, staff, policy makers, and the families we serve, simple but credible methods of cost analysis are needed.

This presentation will highlight a cost-analysis resource from the FRIENDS National Center for Community-Based Child-Abuse Prevention (FRIENDS) that has been adapted for use by respite programs. The tool highlighted in this presentation is free and easily accessible to the public.

In this workshop, we will explore why and how to conduct cost analysis of your short break or respite programs. The presenters will help attendees identify the data needed for producing accurate estimates of the cost to deliver services and for estimating cost avoidance and return on investment.

1:15 pm - 1:50 pm Breakout Session J

Virginia Lifespan Respite Voucher Program: Successes, Challenges and Lessons Learned

Nick Slentz and Liza White

Virginia Department for Aging and Rehabilitative Services

The Virginia Lifespan Respite Voucher Program (VLRVP), supported by grants from the Administration for Community Living, has worked in partnership with the Virginia Caregiver Coalition (VCC) to provide desperately needed respite opportunities to Virginians since 2009.

This session will provide a detailed overview of how the Virginia Lifespan Respite Voucher Program is designed, how it is implemented, the successes of the program design and overcoming the challenges associated with it. It will also discuss best practices and knowledge gained from the effective implementation over the last decade. Demographic data about individuals served by the program will be highlighted.

1:55 pm - 2:30 pm Breakout Session K

Advancing the Breakroom in South Carolina's Faith Communities

Nicholas Julian, Kathy Mayfield-Smith, Joe Ward

South Carolina Respite Coalition

In the SC Respite Coalition's initiative to engage with faith communities, we have expanded our work over the last year to include piloting respite Breakrooms in several churches across the state. Presenters will provide program specifics, lessons learned in implementation, status and adjustments through Covid19, and the building of the Breakroom as a model for other communities.

Our current implementations have focused on congregations of different sizes, different geographical settings, and with varying levels of technical support needs. Because of the diversity in the types of congregations we have worked with, we will address the unique challenges faced in this project, as well as successes and possibilities for wider replication. Work was expanded to include providing greater technical support to congregations to help them learn to be information and referral partners, identify caregiver and care recipient needs, and build partnerships to assist families.

Session participants will learn about commonalities, challenges and the desire among congregations to serve and mobilize to meet the community need for respite programming and expanded service.

2:35 – 3:10 PM CT Breakout Session L

Innovative Insight: Understanding Your Needs by Identifying Yourself as a Caregiver

Megan Schwalm

Tennessee Respite Coalition

To address barriers to respite, the Tennessee Respite Coalition and Tennessee Technical University have partnered to create an innovative website with the goal of helping people identify as caregivers and to provide online trainings to assist them in more effectively caring for their loved ones. The presentation will introduce participants to our immersive, 360-degree experience allows users to virtually visit a house that has been altered to accommodate a family member in need, accompanied by four voices reflecting on their daily lives taking care of their loved one.

In addition to helping people identify as caregivers, the website contains four training modules for Grooming, Morning Routine and Meal Times, Refusal to Take Medication, Responding to Repetitive Questions, Bathing. These modules provide pre- and post- tests that result in certificates to show completion of the training.