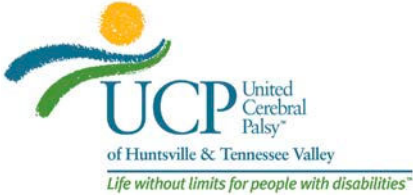




# RAISE and ENGAGE

## LAUNCH RESPITE NOW

2025 National Lifespan Respite Conference  
April 1-3, 2025 ✨ Huntsville, AL





**UCP** United  
Cerebral  
Palsy™

of Huntsville & Tennessee Valley

*Life without limits for people with disabilities™*

Empowering individuals of all abilities through  
comprehensive services and community support.

[ucphuntsville.org](http://ucphuntsville.org)



2025 National Lifespan Respite Conference  
April 1-3, 2025 + Huntsville, AL

**Proud sponsor of the 2025 National Lifespan Respite Conference**

# Welcome

Share your conference pictures and highlights on LinkedIn, Instagram, X, and Facebook with [#LaunchRespite2025](#).

## Welcome to Huntsville and to the 2025 National Lifespan Respite Conference!

We are grateful to gather with you to celebrate our many accomplishments to advance the [National Strategy to Support Family Caregivers](#) since its release by the Administration for Community Living in 2022. The Strategy, developed jointly by the [RAISE Family Caregiving Advisory Council](#) and the [Advisory Council to Support Grandparents Raising Grandchildren](#), includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors, including actions that each of us can take, to advance supports to strengthen the nation's more than 53 million family caregivers.

The theme for the conference, **RAISE and ENGAGE – LAUNCH RESPITE NOW**, is not only a nod to the incredible history of the space industry in Huntsville, AL, also known as Rocket City USA, but also is a call to action. Much has been accomplished at the federal, state and local levels to address caregiver needs since we last met, but we have a long way to go. The conference will provide opportunities to create the space, inspiration and momentum needed to prepare our organizations to take flight in the mission to support the nation's family caregivers.

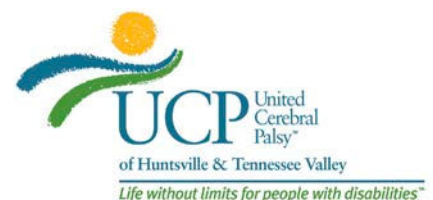
The Lifespan Respite grantees and their State Respite Coalition partners play key roles in the future of respite. States can take pride in their accomplishments – expanded respite voucher programs, exemplary volunteer and faith-based respite initiatives, innovative respite and caregiver support programs, easier access to respite services, and hundreds of new respite workers and volunteers trained from coast to coast.

Here in Alabama, Alabama Lifespan Respite is forging new innovations for respite and caregiver support every day. They have used their Lifespan Respite grant funds to leverage additional state funds, ignite innovation through community respite initiatives, support the mental health and well-being of caregivers, and most importantly, share their successes and expertise with the rest of the national respite network.

**RAISE and ENGAGE – LAUNCH RESPITE NOW** aptly reflects these successes, but more importantly challenges each of us to demonstrate our leadership in advancing the National Strategy to Support Family Caregivers by growing new respite care opportunities and streamlining respite access in our states and communities. During this changing and challenging time, we will rethink how we address the ever-growing need for meaningful respite and caregiver supports, and help ensure that services remain available and person- and family-centered.

Take advantage of everything the conference and Huntsville have to offer and let's **RAISE and ENGAGE – LAUNCH RESPITE** together.

### Your 2025 National Lifespan Respite Conference Hosts:





# Huntsville



## Progressive and Historically Rich

*Because we're always looking to the future without forgetting the past, Huntsville is simultaneously one of Alabama's most progressive and historically rich cities.*

*Centrally located in the northernmost part of Alabama, Huntsville is the largest city in the state with more than 1.2 million residents in the Huntsville metro area.*

*Huntsville is one of the most recognized cities in the Southeast – consistently named as one of the best places to live and work by a variety of national publications. Our city is regularly named as a premier location for both business and quality of life.*

*Technology, space, and defense industries have a major presence here with the Army's Redstone Arsenal, NASA's Marshall Space Flight Center, and Cummings Research Park—the second largest research park in the country and the fourth largest in the world. It is one of the world's leading science and technology business parks, with a mixture of Fortune 500 companies, local and international high-tech enterprises, U.S. space and defense agencies, thriving business incubators, and competitive higher-education institutions.*

*Our quality of life is second to none – with a variety of educational, recreational, and cultural opportunities. We successfully combine the rich heritage of Southern hospitality with innovative high-tech ventures and cultural diversity.*

*Whether you're a space enthusiast, a history buff, or simply looking for a fun and engaging city to explore, Huntsville has something to offer everyone!*

Share your conference pictures and highlights on LinkedIn, Instagram, X, and Facebook with [#LaunchRespite2025](#).



# Conference Sponsors

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## National Conference Planning Committee

**Cristina Amedeo** ✨ Family Caregiver Alliance of Rhode Island

**Jenny Andrews** ✨ South Carolina Department on Aging

**Megan Bettinger** ✨ Colorado Respite Coalition, Easterseals Colorado

**Julie Carden** ✨ UCP Huntsville

**Tracy Cieniewicz** ✨ Alabama Lifespan Respite

**Abbey Derepentigny** ✨ New York State Office for The Aging

**Talena Ford** ✨ Oklahoma Lifespan Respite Program, Oklahoma Human Services

**Cory Lutz** ✨ Helping Hands of Vegas Valley and Nevada Respite Care Coalition

**Denise Meza** ✨ Family Caregiver Alliance of Rhode Island

**Lita Nelson** ✨ Arizona Division of Aging and Adult Services

**Toy Pilot** ✨ South Carolina Respite Coalition

**Lisa Schneider** ✨ Respite Care Association of Wisconsin

**Adrienne Smith** ✨ New Mexico Caregivers Coalition

**Cheryl Smith** ✨ UCP Huntsville

**Tina Yurik** ✨ Illinois Respite Coalition



# The Westin Huntsville

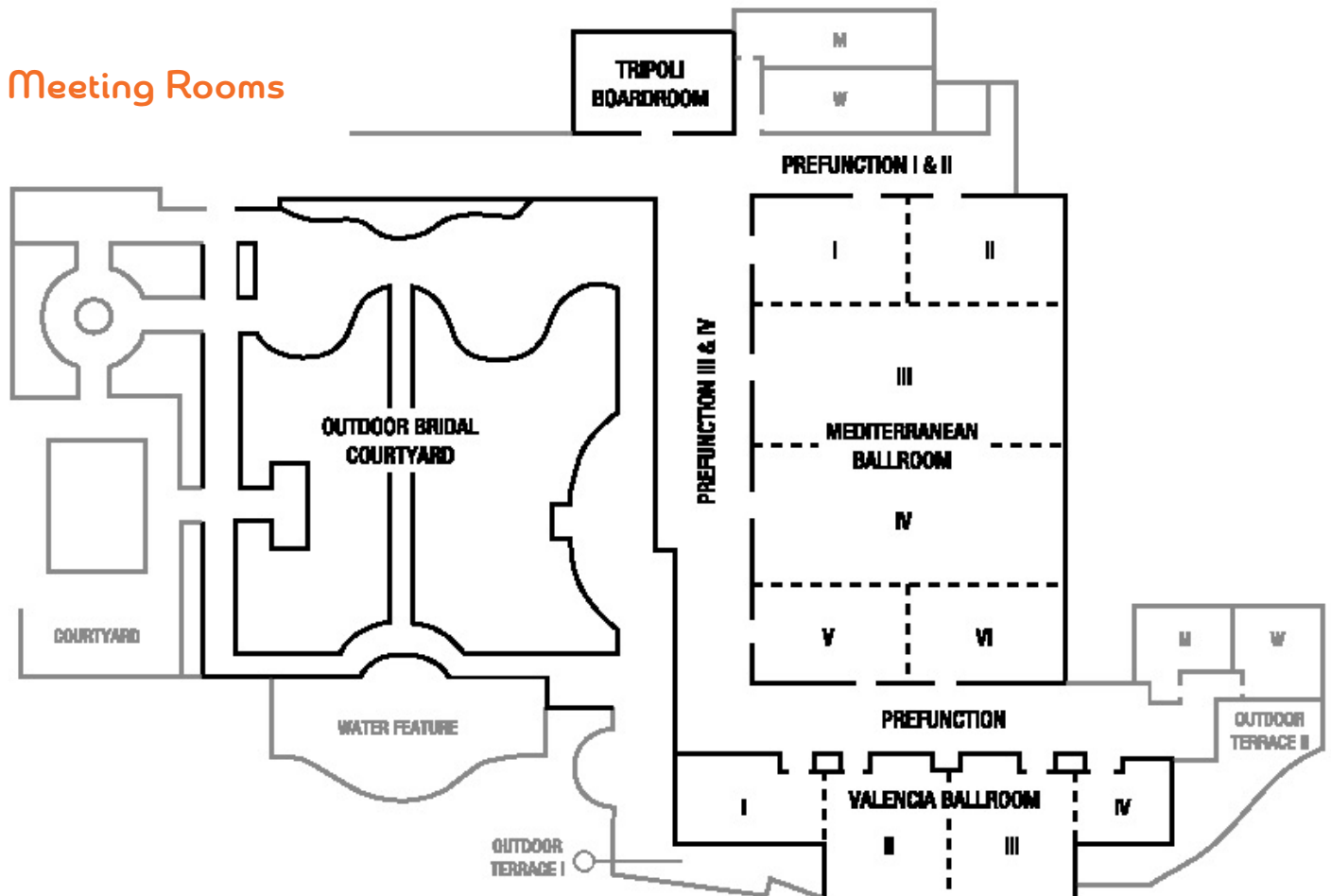
6800 Governors West, NW, Huntsville, AL 35806 • 256-428-2000

**Free Wifi available:** *Westin\_Guest* (no password required)

The Westin Huntsville offers convenient access to several of the city's most beloved attractions, such as Huntsville Botanical Garden and the U.S. Space and Rocket Center. MidCity District, Town Madison and Toyota Field are other favorite dining and entertainment districts nearby. The Westin is about 8 ½ miles from Huntsville International Airport.



## Meeting Rooms





## ALABAMA LIFESPAN RESPITE

Increasing access to  
and availability of  
high-quality respite  
resources for  
caregivers in  
Alabama since 2000.

## Alabama Lifespan Respite Coalition 2024-2027

- Rep. Danny Garrett, Chair—House Ways & Means Education Committee
- Sen. Will Barfoot, Chair—Senate Judiciary Committee
- Rep. Paul Lee, Chair—House Health Committee
- Sen. Tim Melson, Chair—Senate Healthcare Committee
- Rep. Laura Hall, House Health Committee Ranking Minority Member
- Nick Nyberg, Alabama Department of Senior Services
- Ginger Carmack—Alabama Department of Medicaid
- Vivian Amy Warren—Alabama Department of Mental Health
- Darryle Powell—Alabama Council on Developmental Disabilities
- Cheryl Smith—UCP Huntsville
- Amy Lamb-Eng—Alabama Head Injury Foundation
- Karen Pettaway—Community Respite Provider
- Nikki Poe—West Alabama Regional Council Area Agency on Aging
- Theresa Vollar—Birmingham VA Healthcare System
- Beau Green—Right at Home
- Dr. Nicole Ruggiano—University of Alabama
- Dr. Rachel Winston—University of North Alabama
- Sallye Longshore—Alabama Department of Child Abuse and Neglect Prevention
- Hattie Thomas—Community Respite Provider
- Jennifer C. Blakely—Governor’s Office on Disability
- Kristin Moore—Alabama Department of Rehabilitation Services
- Tonia Bell—Alabama Department of Human Resources
- Gregory Dodd—Alabama Department of Public Health
- Gina Germany—Community Respite Initiative
- Maria Gutierrez—Family Caregiver, Auburn University Regional Autism Network
- Caneilia Patterson—Family Caregiver, Bringing Up Down Syndrome North Alabama
- Chenique Jeffress—Autism Support of Alabama
- Lance Lee—Alabama Hospice Organization
- Logan Lutz—Alabama Home Health Provider



***A statewide program of UCP Huntsville***







# ARCH

National Respite Network  
AND RESOURCE CENTER

***The MISSION of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.***

The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community; the National Respite Coalition, the policy and advocacy division of ARCH; and the Lifespan Respite Technical Assistance and Resource Center, which is funded by the Administration for Community Living in the U.S. Department of Health and Human Services to help state agencies, state respite coalitions, and the respite network improve and expand respite services, access, and affordability for all family caregivers.

ARCH was established with funding from the U.S. Children's Bureau in 1990. The first national respite conference was sponsored by the Children's Bureau with ARCH's assistance in the fall of 1991 in Washington, DC. In 1998, ARCH took on a lifespan perspective and became the main sponsor of the annual national respite conference with state respite coalition collaboration and has hosted a national U.S. event nearly every year since then. ARCH has also been a leader in the international respite network as a cofounder of the International Short Break Association. In 2003 and again in 2021, ARCH was privileged to serve as a cohost of the International Short Break Association Conferences.



[archrespite.org](http://archrespite.org)

ARCH, which stands for Access to Respite Care and Help, is a program of Families and Communities Rising, Inc. in Durham, NC.

# Innovative and Exemplary Respite Services



*The ARCH National Respite Network and Resource Center is proud to recognize four Innovative and Exemplary Respite Services for 2025 from across the U.S.*

*Each respite service met a stringent set of selection criteria and all have outstanding programs that address the needs of family caregivers of children, adults or older adult family members. By recognizing exceptional respite services, ARCH hopes to encourage the expansion and replication of quality respite to meet the growing need. To read more about the application and selection process, and details about each program, visit the ARCH website at [archrespite.org/provider-resources/innovative-and-exemplary-respite-services](https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services).*



*Accepting for Duet is Patricia Dominguez, MSW, Director of Kinship Care Services.*

## **Duet: Partners in Health & Aging – Kinship Care Services**

Located in Phoenix, AZ, Duet: Partners in Health & Aging – Kinship Care Services provided 7,600 hours of respite to 144 grandfamilies during the past year. Kinship Care services were created at Duet in 1995 when staff members noticed that a growing number of seniors stopped attending programs because they had new responsibilities raising their grandchildren. Kinship Care Services chose a flexible voucher service model within a personalized, family-focused approach, allowing the program to tailor support to each caregiver's unique needs and preferences. In addition, grandfamilies participate in shared respite opportunities through intergenerational social outings. Highly valued by grandfamilies, 1,500 shared respite hours were provided during the past year. Coaching on respite time use, monitoring of family needs for clothing, housing, assistance in applying for benefits, and financial support for grandchildren's activities, such as school sports, complement respite services. Resources to support this program are diversified and include local business support. A Grandparents Advisory Board works actively at all program levels. Website: [duetaz.org](https://duetaz.org)

## Neighbor Network of Northern Nevada's Community Care Program

Serving 12 counties in Northern Nevada, Neighbor Network of Northern Nevada's Community Care Program was established five years ago. Guided by a human-centered design approach for creating a community village model, this program serves more than 170 adults over the age of 18 who have conditions related to aging and disability, including intellectual disabilities and dementia. The program model includes five or more hours of respite care weekly, in the home and community, at no cost to families, provided by trained Community Care Partners. Person-centered planning supports the development of trusting caregiver-program relationships and allows programs to understand and configure services according to individual family need. Care recipients receive services that are individually tailored, matching their preferences and needs. Services include social and recreational opportunities, personal care, and transportation. Website: [neighbornv.org/what-we-do/community-care/respite-care](http://neighbornv.org/what-we-do/community-care/respite-care)



## Neighbor Network of Northern Nevada

*Accepting for Neighbor Network of Northern Nevada's Community Care Program is Amy Dewitt-Smith, MPA, Founder and Executive Director.*



*Accepting for Pause for Parents, Play for Kids is Lisa McCoon, the organization's CEO.*

## Pause for Parents, Play for Kids

Pause for Parents, Play for Kids, located in Liberty Township, Ohio, was established 10 years ago in response to local planning data showing that 100% of parents of children with disabilities in the community reported feeling isolated with a decreased support system. This center-based, drop-off respite model was piloted in a church setting and has grown to serve 1,700 children and caregivers. Children receive a developmentally appropriate and trauma-informed individualized program curriculum, while fostering caregivers' resilience, physical and mental health, positive social connections, a sense of belonging, and joy. Sibling workshops are offered, and although the program is not religiously based, an in-church ministry service works to make Sunday School meaningful to children with developmental and learning differences while their caregivers attend worship services. Six hundred active volunteers are seen as essential to the program's mission. Website: [pauseforparents.org](http://pauseforparents.org)

## Tennessee Caregiver Coalition, Sumner Senior Volunteer Program

Sumner Senior Volunteer Program, a program of Tennessee Caregiver Coalition based in Nashville, TN, replicates Tennessee's AmeriCorps-funded Senior Companion Program, and provides four or more hours of in-home or virtual respite per week to more than 30 families. For those families opting for virtual respite (about half of those served), tablets or Chromebooks and training and support in their use are provided to caregivers. This volunteer-provider program aims to reduce caregiver stress, improve family relationships, and enhance caregivers' ability to care for their loved ones. Person- and family-centered planning, followed by volunteer-coaching in respite time use, and continuing check-ins with caregivers help to assure that services continue to meet family needs. Volunteers work up to 40 hours weekly, and although recruitment has been challenging, once on-board, 100% of the 17 volunteers have continued with the program. Website: [tncaregiver.org](http://tncaregiver.org)



## TENNESSEE CAREGIVER COALITION

*Accepting for Sumner Senior Volunteer Program is Megan Schwalm, PhD, Executive Director of the Tennessee Caregiver Coalition.*

**OK ABLE Tech: Respite Kits Program**, Stillwater, OK, **Share the Care**, Winter Park, FL, and **Stepping Up Again, Grandparents Raising Grandchildren**, Lawrence, MA, were recognized as **Rising Stars**.





# Conference Tracks



## DISCOVER through Research and Evaluation

As service providers and caregivers make a case for respite availability and funding, a solid evidence-base for respite is essential. Research provides an understanding of the health and well-being of family caregivers and the overall effect of respite on societal outcomes, including cost-benefits. Good data collection is important for continuous quality improvement in respite services and to ensure effective service delivery. Presenters in this track will present findings from evaluations of lifespan respite activities, respite models, training initiatives, alternative respite and support intervention strategies, and statewide needs assessments. The ARCH Respite Research Initiative with a focus on Measuring the Value of Respite model will be presented.



## REFUEL with Advocacy, Networking and Sustainability

We have come to understand that our collective efforts to sustain the important work we do in caregiving and respite is inextricably linked to the changing economic, social and political environment as well as to successful networking strategies and partnerships. Presentations will explore financing strategies for sustainability, unique partnerships, successful coalitions, advocacy, and other elevated contexts for providing, promoting and sustaining respite.



## LAUNCH Innovative Services and Systems

This track is designed to highlight successful models, innovations, and exemplary approaches to providing planned and crisis respite care for all ages, disability groups, and various populations. Newly raised and non-traditional approaches to respite for all populations will also be shared.



## PROPEL the Respite Workforce

This track focuses on real-life solutions to the nationwide shortage of well-trained direct care workers and respite providers. Sessions will focus on ways to boost caregiver confidence in respite, including training to improve the safety and quality of care, and strategies to increase the pool of reliable and qualified respite providers and care options. Approaches to innovative recruitment and retention strategies, as well as national strategies to formally connect family caregivers and direct care workers to enhance overall care will be presented.



## NAVIGATE Support for Working Caregivers

A significant majority of family caregivers, at least 60 percent, are in the labor force, but to enable them to continue to work and provide care, a more responsive and supportive workplace is needed. Not only are the health and financial well-being of these caregivers at-risk, businesses may be losing billions of dollars annually from lost productivity, replacement costs for employees who quit because of overwhelming caregiving responsibilities, absenteeism, and workday interruptions. This track is intended to explore successful strategies to ensure respite and other caregiver supports are available and accessible to working caregivers.



## ENGAGE Family Caregivers

This track is geared toward family caregivers and those working with family caregivers who want to learn more about successful caregiving strategies, meaningful respite, resources that support caregivers, use of technology to support respite, and the benefits of respite and caregiver wellness programs. How to engage family caregivers to use respite services as well as participate in respite and caregiving coalitions, planning, advocacy, and evaluation will also be discussed.



## EXPLORE the Universe of Lifespan Respite

This track features Lifespan Respite grantees and their partners who will highlight their successful service delivery and systems change grant activities. Through the federal Lifespan Respite Program, the U.S. Administration for Community Living awards competitive grants to state agencies in partnership with state respite coalitions and others to develop statewide coordinated systems of community-based respite services for family caregivers; provide gap-filling planned and emergency respite; and build respite capacity through provider training and recruitment and new volunteer and faith-based initiatives.





Every spring, the Huntsville Botanical Gardens comes to life. Above is the Damson Aquatic Garden.

# Join us on our official event app!

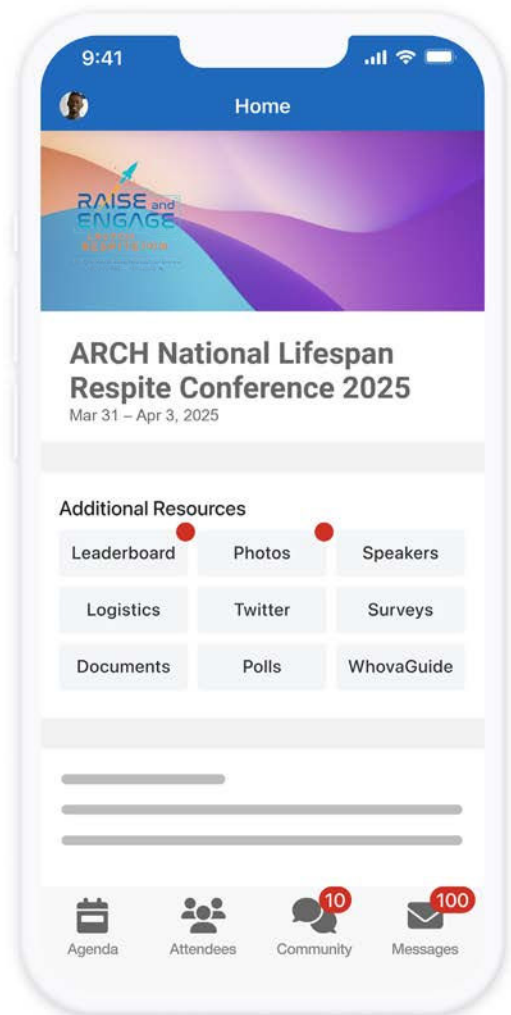
We're using *Whova* as our official event app. Download the app and join our event to:

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Scan this code for the link or search "Whova - Event and Conference App" on the App Store or Google Play.

Event Invitation Code: 05nt4c2ygm







# Conference Schedule

## Monday Evening, March 31, 2025

6:00 – 8:00 PM **Early Registration**

6:00 – 8:00 PM **Networking Reception for Lifespan Respite Grantees, Partners, and Guests** (by invitation only)

*Valencia Ballroom*

## Tuesday, April 1, 2025

8:00 – 9:00 AM **Registration and Breakfast for Lifespan Respite Grantee and Partner Learning Symposium Attendees**

9:00 AM – 3:00 PM **Lifespan Respite Grantee and Partner Learning Symposium** (by invitation only)

*Valencia Ballroom*

## Tuesday Evening, April 1, 2025

3:00 – 8:00 PM **National Conference Registration**

6:00 – 8:00 PM **National Respite Conference WELCOME RECEPTION** *Outdoor Bridal Courtyard*  
**RECOGNITION of ARCH 2025 Innovative and Exemplary Respite Services**

PRESENTER: **Susan Janko Summers, PhD**  
*ARCH National Respite Network and Resource Center*



ARCH is honored to recognize the 2025 Innovative and Exemplary Respite Services. These respite services were selected from a national pool of applicants. Each recognized service met a stringent set of criteria for selection, and all have outstanding programs that address the needs of family caregivers of children, adults and/or older adult family members.



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**PROPEL**  
the Respite  
Workforce



**NAVIGATE**  
Support for Working  
Caregivers



**ENGAGE**  
Family Caregivers



**EXPLORE**  
the Universe of  
Lifespan Respite

Individuals who will accept the recognition for their respite programs are:

- **Patricia Dominguez, MSW** • *Director, Kinship Care Services, Duet: Partners in Health & Aging, Phoenix, AZ*
- **Amy Dewitt-Smith, MPA** • *Founder/Executive Director, Neighbor Network of Northern Nevada (N4), Reno, NV*
- **Lisa McCoon** • *CEO, Pause for Parents, Play for Kids, Liberty Township, OH*
- **Megan Schwalm, PhD** • *Executive Director, Tennessee Caregiver Coalition, Nashville, TN*

Read more about the 2025 Innovative and Exemplary Respite Services on page 8.

## Wednesday Morning, April 2, 2025

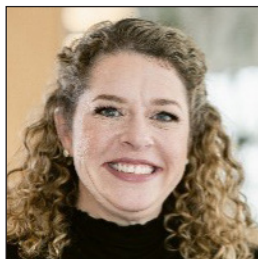
**7:00 AM – 5:00 PM** Registration/Information Table

**7:30 – 9:00 AM** Breakfast

**9:00 – 10:30 AM** **WELCOME and OPENING SESSION**

*Mediterranean Ballroom III and IV*

- **Jill Kagan, MPH** • *Director, ARCH National Respite Network and Resource Center*
- **Cheryl Smith** • *CEO, United Cerebral Palsy (UCP) Huntsville and Tennessee Valley*
- **Darryle Powell, MS** • *Chairman, Alabama Lifespan Respite Coalition, and Executive Director, Alabama Council for Developmental Disabilities*



### KEYNOTE PRESENTATION

**Kristin Scroggin** • *Managing Partner and Lead Trainer  
genWHY Communication Strategies, Huntsville, AL*

***Generation “THEM”:*** *Bridging the Generational Divide for  
Caregivers*

Embark on a journey with Generation “THEM,” a dynamic exploration of the ‘WHY’ behind each American generation’s unique perspectives. This presentation equips caregivers and the professionals who work alongside them – whether supporting children, young adults, or older individuals – with the tools to foster understanding, improve communication, and build stronger relationships across generations. Gain valuable insights into generational norms and discover strategies to navigate differing expectations with empathy and effectiveness. With a light-hearted approach, this session will illuminate the quirks that make us uniquely human while providing practical takeaways for caregivers and respite professionals in diverse settings.

**10:30 – 11:00 AM** Break



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11:00 AM – 12:00 PM

## Breakout Session A



**EXPLORE**

### Innovations Working with Diverse Populations to Raise, Engage, and Launch Respite in Washington State

*Valencia III*

- **Rosalyn Alber** • *Kinship and Lifespan Respite Program Manager, Aging and Long-Term Support Administration, Washington State Department of Social and Health Services, Lacey, WA*
- **Dana Allard-Webb** • *Family Caregiver Support Program Manager, Aging and Long-Term Support Program, Washington State Department of Social and Health Services, Lacey, WA*

The Washington State Lifespan Respite Program (LRW) seeks to increase respite participation of underserved communities. Caregiver voices are vital in learning about needs, fears, and barriers they may face when reaching out for help. During this presentation, we will discuss some of the strategies currently being used in Washington State to address these issues. Highlights include the work with Tribal and Latinx communities and increasing opportunities for caregivers and receivers to be included in programming.



**REFUEL**

### Using the Caregiver Intensity Index to RAISE and Engage Family Caregivers

*Valencia II*

- **Sarah Stephens Winnay** • *Co-Founder, ARCHANGELS, Newton Center, MA*
- **Deana Prest** • *Caregiver Support Program Director, New York State Office for the Aging (NYSOFA), Albany, NY*

In New York State, there are over 4.1 million caregivers providing 2.68 billion hours of unpaid care. More than 50% of caregivers do not self-identify as a caregiver, causing challenges for caregiver engagement. To combat this, the New York State Office for the Aging (NYSOFA) is collaborating with ARCHANGELS, using their Caregiver Intensity Index, to engage caregivers and link them to resources.



**ENGAGE**

### Propelling the Respite Workforce by Developing Student Respite Programs

*Mediterranean II*

- **Kim Whitmore, PhD, RN** • *Assistant Professor, Marquette University College of Nursing, Milwaukee, WI*

Engaging students as respite providers is a great way to Propel the Respite Workforce. Student respite programs are mutually beneficial, ensuring caregivers have access to high-quality respite care, care recipients receive quality supports and another opportunity to ENGAGE in meaningful activities, and students ENGAGE in the realities of caregiving and gain hands-on skills. In this session, you will learn about the Student Respite Program Toolkit developed by the Respite Care Association of Wisconsin.



**PROPEL**





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**LAUNCH**

## USAgings's Innovations in Family Caregiver Services and Supports Initiative: Respite and Trauma-informed Care Action Guides

*Mediterranean III*

- **Cara Goldstein** • Assistant Director, Caregiving Services and Supports, USAgings, Washington, DC
- **Sarah Toevs, PhD** • ARCH Consultant and Professor Emeritus, School of Public and Population Health, Boise State University, Boise, ID
- **Carly Bruski, LMSW** • Assistant Director of Strategic Partnerships, Jewish Federations of North America's Center on Aging, Trauma, and Holocaust Survivor Care, New York, NY

Presenters will highlight the work of USAgings's Innovations in Family Caregiver Services and Supports Initiative and resources that are available through that effort. Attendees will learn about new resources available through the Caregiver Services and Support Action Guide series. The Respite Action Guide will be highlighted along with strategies for applying the information. Additionally, the Person- and Family-Centered Trauma-Informed Care Action Guide and Social Determinants of Health Action Guide will also be presented.



**LAUNCH**

## Implementing a Limited Launch for New or Improved Respite Care Service Programs

*Mediterranean IV*

- **Amy Dewitt-Smith, MPA** • Founder/Executive Director, Neighbor Network of Northern Nevada (N4), Reno, NV

As the founder and executive director of the Neighbor Network of Northern Nevada, Amy Dewitt-Smith has carried the principles of design-thinking, person-centered planning, and full community inclusion throughout her work in aging and disability services. This session will review how to implement a human-centered design approach for respite care services and the importance of addressing community access and inclusion using an innovative, community-focused respite care program design.



**LAUNCH**

## Caregiver Support Services, Offering Comprehensive Support to Caregivers and Their Families to Prevent Child Abuse & Neglect

*Mediterranean V*

- **Larry Cooper, MSW, LCSW** • Executive Vice President of Innovation, Children's Home Network, Tampa, FL
- **Stephen Foshey, BS, CCWS** • Director of Caregiver Support Services, Children's Home Network, Tampa, FL
- **Nicole Ortiz, MS** • Support Services Manager, Children's Home Network, Tampa, FL

The Caregiver Support Services (CSS) program provides a unique opportunity for families who are experiencing acute stressors and/or disability challenges. CSS provides respite in many scenarios that empower the family to gain supports and relief in caregiving, emphasizing self-care. CSS allows for wrap-around services ensuring that resources are in place to provide longevity of support, decreasing the risk of the children entering the dependency system. CSS empowers families through support groups and after care.



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Family Caregivers



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the Universe of  
Lifespan Respite



**ENGAGE**

## RAISE and Engage Family Peer Support Services

*Mediterranean VI*

- **Carol W. Cecil** • *Public Health Advisor, Substance Abuse and Mental Health Services Administration's (SAMHSA) Office of Recovery, Rockville, MD*

This session is focused on family peer support services and how the expansion of those services could assist family caregivers in navigating various systems, reduce feelings of isolation and being overwhelmed, and have a safe place to share their experiences. While this is not directly respite, family peer support services still provide a “sense of relief” or “sense of self-care” as do respite services.



**DISCOVER**

## There's No Break: Parents of Children with Medical Complexity Recommend Peer Navigation to Improve Respite Access

*Mediterranean I*

- **Amy Porter, MD, PhD** • *Physician-investigator, Massachusetts General Hospital, Harvard Medical School, Boston, MA*

This qualitative, ethnographic study confirmed that parents of children with medical complexity identify respite as critical to well-being and sustaining caregiving capacity, yet lack bandwidth to pursue possible services. Findings illuminated parents' creative approaches to finding opportunities to recharge in the absence of formal respite care and amplified their recommendations for supporting respite access through parent-to-parent peer navigation.

**12:00 – 12:30 PM Break**

## Wednesday Afternoon, April 2, 2025

**12:30 – 2:15 PM LUNCH and PLENARY PANEL**

*Mediterranean Ballroom III and IV*

### Screening of Excerpts from the PBS Documentary *Caregiving* and Panel Discussion



This thought-provoking panel discussion will follow a special screening of excerpts from [Caregiving](#), an upcoming two-hour PBS documentary executive produced by Bradley Cooper. Set to air nationwide on PBS in June 2025, the documentary provides an intimate look at the personal stories of caregivers and the complex realities of short- and long-term care, as well as palliative and end-of-life care. We will also learn about the *Caregiving* project's robust national engagement campaign.





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The panel discussion, moderated by Marcus Escobedo, MPA, of the John A Hartford Foundation will feature Josh Carter, Rosalynn Carter Institute for Caregivers, members of the film's production team, and Lynnette Canedy, a family caregiver who appears in the film.



MODERATOR

**Marcus Escobedo, MPA**

*Vice President, Communications and Senior Program Officer  
The John A. Hartford Foundation, New York, NY*

PANELISTS



**Josh Carter**

*Grandchild of President Jimmy  
Carter and Rosalynn Carter  
Spokesman for the Rosalynn Carter  
Institute for Caregivers*



**Christopher Durrance**

*Director & Senior Producer of  
Caregiving  
Ark Media*



**Lynnette Canedy**

*Family Caregiver and 2023 Dole  
Fellow*



**Tom Chiodo**

*Executive Producer of Caregiving &  
Special Projects  
National Productions, WETA/PBS*

2:15 – 2:45 PM **Break**

2:45 – 3:45 PM **Breakout Session B**



**Implementing Goal #1 of the RAISE National Strategy:  
Awareness and Outreach to Family Caregivers**

*Mediterranean IV*

- **Siena Ruggeri** • *Community Engagement Consultant, Community Catalyst, Boston, MA*
- **Megan Schwalm, PhD** • *Executive Director, Tennessee Caregiver Coalition, Nashville, TN*

This presentation will share learnings, best practices, and implementation strategies on awareness and outreach to diverse family caregiver populations. The session will detail national, state, and community-level outreach efforts to implement Goal #1 of the RAISE National Strategy.





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## Stellar Respite Care: A Constellation of Support at Jewish Adoption and Family Care Options (JAFCO's) Children's Ability Center

*Mediterranean III*

- **Lindsay San, MS, BCBA** • Program Director, Jewish Adoption and Family Care Options (JAFCO) Children's Ability Center, Sunrise, FL
- **Shirley Lora Reyes, DMFT, LMFT** • Shelter Supervisor, JAFCO Children's Ability Center, Sunrise, FL
- **Justin Kohlhagen, PsyD** • Executive Director, JAFCO Children's Ability Center, Sunrise, FL

This presentation will explore JAFCO's Constellation of Care model, demonstrating how integrated respite care and supportive services are designed to meet the diverse needs of the entire family. Attendees will learn about trauma-informed, family-centered approaches that empower parents, siblings, and children through tailored services like support groups, educational advocacy, and enrichment programs, creating a lasting, positive impact on families raising children with developmental disabilities that extends far beyond respite care.



**REFUEL**

## Building Elder Justice Strong Communities

*Mediterranean II*

- **Robyn James** • Director, Elder Justice Center of Alabama, Alabaster, AL

Building Elder Justice Strong Communities can make the difference for older adults and their family caregivers to be heard, supported, and engaged at home and in their community. All of us play a critical role to ensure communities learn how to become "elder justice strong" and the value it brings to all aging in place initiatives.



**LAUNCH**

## Unseen Barriers: Navigating Memory Loss Care Across Cultural Lines

*Valencia II*

- **Doris Karpeh-Diaz** • Director, Centro De Amigos Social Adult Day Care, Haverstraw, NY

This session explores challenges in providing memory care across cultural differences. Attendees will learn strategies to address language barriers, cultural disconnects, and effective communication through case studies and best practices. Designed for healthcare organizations and community-based providers, this presentation emphasizes culturally competent care to improve engagement and health outcomes for diverse aging populations. Discover how integrating these practices can transform your approach to person-centered care.

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## Breakrooms that Raise and Engage Faith Communities and Volunteers to Re-Launch Respite Now as Part of a Statewide Coalition *Mediterranean VI*

- **Kathy Mayfield Smith MBA, MA** • Associate Director, Institute for Families in Society, University of South Carolina, Columbia, SC
- **Toy Pilot** • Executive Director, South Carolina Respite Coalition, Columbia, SC

With South Carolina's Lifespan Respite grant, we developed a model for faith- and community-based respite for replication. Presenters will discuss the Breakroom model, strategies to support development using the How To Guide, evidence of effectiveness, and lessons learned. We will share challenges during COVID, ways we broadened the vision, expanding to engage partners in the broader coalition through regional events, enabling Breakrooms to be a center for educating caregivers and building circles of support.



**LAUNCH**

## From Campus to Community: Respite Care through Service Learning, Internship, and Employment Opportunities for College Students *Mediterranean V*

- **Ashley Woodman, PhD** • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA

We will present an overview of the Campus to Community Respite Care Program at the University of Massachusetts Amherst. Starting in 2019, this program has connected undergraduate students in psychology, education, nursing and other disciplines with local families raising children, adolescents, and adults with intellectual and developmental disabilities. We will present feedback gathered through caregiver interviews and student surveys as well as evidence of student growth in respite care provider competencies defined by a national expert work group convened by ARCH.



**PROPEL**

## A Mindful Moment for Respite: Brief Relaxation Interventions for Families *Valencia III*

- **Emily Davidson, MD, MPH, RYT** • Attending Physician, Boston Children's Hospital, Attending Physician, Boston, MA

This session will discuss the impact of caregiving on physical and mental health and provide participants with an experience of relaxation techniques (chair yoga and meditation) that can be used to mediate stresses of caregiving. A tool kit including other brief mindfulness practices and resources will be provided.



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## National Respite Care Provider Training: Final Evaluation Results

*Mediterranean I*

- **Kim Whitmore, PhD, RN** • *ARCH Consultant and Assistant Professor, Marquette University College of Nursing, Milwaukee, WI*

The ARCH National Respite Network and Resource Center and the Respite Care Association of Wisconsin, in collaboration with the National Academy for State Health Policy, developed the National Respite Care Provider Training. The training, along with a unique recruitment strategy, were field tested in ten states, yielding a wealth of data on the success and challenges of the initiative. In this session, the presenter will share the final evaluation results from state data that was collected by the pilot sites, from interviews with respite learners, and from an analysis of social network mapping.

**3:45 – 4:00 PM Break**

**4:00 – 5:00 PM Breakout Session C**



**ENGAGE**

## Beyond Respite: Creating a Supportive Community for Caregivers

*Mediterranean I*

- **Anisha Bell** • *Helpline Coordinator, Tennessee Caregiver Coalition, Nashville, TN*
- **Breion Dixon** • *Outreach Program Manager, Tennessee Caregiver Coalition, Nashville, TN*

This presentation will showcase the Tennessee Caregiver Coalition (TCC)'s transformation following caregiver feedback in 2023. Recognizing challenges like social isolation and the need for education, TCC adopted a holistic approach to foster community among caregivers. The name change reflects this shift, enhancing programming to promote networking and resource sharing, particularly for underserved populations. Participants will learn the value of caregiver input and how to start creating their own communities through events.



**LAUNCH**

## Reclaiming Joy Together- A Community Response to Dementia

*Mediterranean VI*

- **Daphne Johnston** • *Founder and Executive Director, Respite for All Foundation, Montgomery, AL*

The Respite for All Foundation inspires and supports the launch of volunteer-based communities that provide joyful environments for individuals living with dementia. RFA's approach is radically new as it utilizes countless volunteers to blur the line between volunteer and participant and create an opportunity for all to contribute. Attendees will learn why faith communities are poised to lead sustainable local respite groups and learn about our highly successful volunteer recruitment strategy.





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## Caregivers SOAR: A Model for Sustainable, Community-Driven Respite Services

*Mediterranean V*

- **Kimberly Martin, M.Ed., LMFT** • *Assistant Vice President, Child and Family Services at Riverside Community Care, Dedham, MA*

Discover Riverside Community Care's Caregivers SOAR program, an innovative approach to community-based respite services blending traditional mental health support with person-centered coaching. This model meets caregivers' immediate needs while fostering resilience and personal growth through flexible engagement options. By integrating unique roles like Sustainability Coaches and Family Partners, SOAR empowers caregivers to navigate complex systems effectively. Join us to explore how this transformative program enhances support for caregivers and youth, promoting well-being and community connection.



**EXPLORE**

## Solidifying the Bedrock of Successful Lifespan Respite Care Programs

*Valencia II*

- **Kate Rasulova, MPA** • *Planner, Planning, Policy and Program Development Unit, Delaware Division of Services for Aging and Adults with Physical Disabilities, Newark, DE*

Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)'s research, in collaboration with Guidehouse Consulting, explores enhancements to respite care services, aligning with the goals of the National Strategy to Support Family Caregivers. The study emphasizes a comprehensive, data-driven approach to improving respite care, integrating feedback from caregivers and stakeholders. Key findings highlight the need for flexible, culturally competent care options, addressing caregiver burnout, and expanding service menus. The presentation will cover data gathering methods, translating research into practice, and systems change through successful partnerships.



**DISCOVER**

## College Partners Rising to Engage Their Community Through Respite

*Mediterranean II*

- **Rachel Winston, DNP, RN** • *Nursing Faculty/Respite Program Coordinator, University of North Alabama, Florence, AL*

This presentation will help academic institutions better understand the unique benefits of hosting a local respite program. Respite programs provide families of children with special needs with short-term periods of relief from often daunting caregiver responsibilities. Additionally, the respite program provides college students valuable experiential learning opportunities and it affords the college a means of serving the local community.



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## Respite Collaboration in Model Development, Sustainability, and Funding

*Mediterranean III*

- **John Tyler** • Senior Philanthropic Advisor, The Philanthropic Initiative/Exhale, Boston, MA
- **Phyllis Gunning, MPH** • Director of Network Development, Western New York Integrated Care Collaborative, Buffalo, NY
- **Daysi Ball** • Director, BFNC Life Center, Buffalo Federation of Neighborhood Centers, Buffalo, NY

Exhale, The Family Caregiver Initiative, was established in 2019 to support innovation and expansion of respite services for caregivers of older adults. Respite organizations established partnerships to implement programs for family caregivers. As grant funding ends, Western New York Integrated Care Collaborative – a Community Care Hub – assists organizations in sustainability planning through a community-based business model. A case study will describe how one program benefitted from the partnerships and access to resources in planning for future sustainability.



**ENGAGE**

## Assistive Technology Kits for Caregiver Respite

*Valencia III*

- **Shelley Gladden** • Assistant Director, Oklahoma ABLE Tech, Stillwater, OK
- **Talena Ford** • Programs Administrator, Community Living, Aging and Protective Services (CAP), Oklahoma Human Services Grants and Coalitions Unit, Oklahoma City, OK

This presentation introduces the “Community Partners Respite Program,” an innovative initiative utilizing Assistive Technology (AT) kits to provide temporary relief to family caregivers. Learn about the program’s goals, the types of AT kits available, and the positive impact of AT on caregiver well-being and the lives of those receiving care.



**LAUNCH**

## Integrating Direct Care Workers and Family Caregivers

*Mediterranean IV*


- **Conor Callahan** • Family Caregiving Lead, ADvancing States, Arlington, VA
- **April Young** • Senior Director of Strategic Initiatives, ADvancing States, Arlington, VA

Without family caregivers and direct care workers, the long-term services and supports (LTSS) system cannot function. The two groups, however, are rarely formally connected in meaningful ways. This session will highlight recent efforts by state and local governments, managed care organizations, and community-based organizations to promote caregiver integration across care teams, matching service registries, case management and caregiver training, and research and data collection. Presenters in this workshop will share about two projects funded through the support of The John A. Hartford Foundation – Together in Care and the Cross-State Caregiving Collaborative – and engage the audience in brainstorming other possibilities to effectively support these critical groups.



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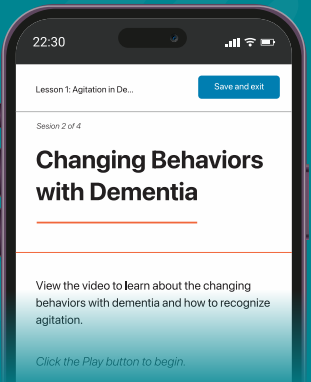
**5:00 – 8:00 PM DINNER on your own**



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## Thursday Morning, April 3, 2025

**7:30 AM – 3:00 PM Registration/Information Table**

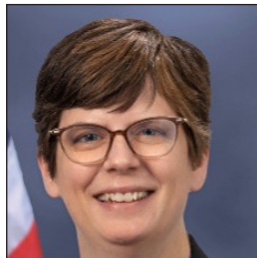
**7:30 – 8:30 AM Breakfast**

**8:30 – 9:45 AM MORNING PLENARY SESSION**

*Mediterranean Ballroom III and IV*

KEYNOTE PRESENTATION

### *National Strategy to Support Family Caregivers: Progress and Next Steps*



**Kari Benson (invited)** • Deputy Assistant Secretary for Aging, Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services, Washington, DC



**Jonathan Cottor, MBA, MPH** • Co-chair of the RAISE Family Caregiving Advisory Council, Chief Executive Officer and Founder, National Center for Pediatric Palliative Care Homes and Children's Respite Homes of America

**9:45 – 10:15 AM Break**

**10:15 – 11:15 AM Breakout Session D**



### **Supporting Working Family Caregivers in South Carolina: A Pilot Program**

*Mediterranean I*

- **Jennifer Brewton, LMSW** • Caregiver and Alzheimer's Resource Division Director, South Carolina Department on Aging, Columbia, SC
- **Lauren McNally, LMSW** • Deputy Finance Director, Trident Area Agency on Aging, Charleston, SC

This workshop will discuss the creation, implementation, and results of a successful pilot program designed to support working family caregivers in South Carolina's Trident Region, and its subsequent expansion statewide. The program aims to help caregivers balance work and family responsibilities by offering reimbursement of out-of-pocket expenses for in-home or adult day services. This support allows caregivers to afford care for their loved ones while remaining in the workforce.



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## Caregiver to Caregiver Respite Network: A Community of Caregiving Rooted in Shared Experience

*Mediterranean II*

- **Elizabeth Bostic** • Assistant Director, Division for Children and Youth with Special Health Needs, Massachusetts Department of Public Health, Boston, MA
- **Ashley Woodman, PhD** • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA
- **Valeryia Pedersen** • Director, Caregiver to Caregiver Respite Network, Federation for Children with Special Needs, Boston, MA

This presentation highlights the origin, planning and implementation of Caregiver to Caregiver (C2C) Respite Network, a statewide network of families who have children with disabilities, medically complex needs or mental health challenges up to the age of 26 and support each other by providing and receiving respite. Attendees will gain insight on data around the respite provider crisis, C2C program logistics, participant feedback and program evaluation completed in partnership with University of Massachusetts Amherst.



**LAUNCH**

## Introducing the 2025 Innovative and Exemplary Respite Services

*Mediterranean III*

- **Susan Summers, PhD** • Senior Evaluation Consultant, ARCH National Respite Network and Resource Center, Seattle, WA
- **Amy Dewitt-Smith, MPA** • Founder/Executive Director, Neighbor Network of Northern Nevada (N4), Reno, NV
- **Patricia Dominguez, MSW** • Director, Kinship Care Services, Duet: Partners in Health & Aging, Phoenix, AZ
- **Lisa McCoon** • CEO, Pause for Parents, Play for Kids, Liberty Township, OH
- **Megan Schwalm, PhD** • Executive Director, Tennessee Caregiver Coalition, Nashville, TN

During this session, Susan Summers with the ARCH National Respite Network and Resource Center will introduce model respite services recognized by ARCH as Innovative and Exemplary in 2025. All serve different populations and represent unique approaches to providing respite. Presenters will discuss the components of their services that make them exceptional, innovative, sustainable, and worthy of national replication.

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## Expanding Group Respite to Multi-Generational Service for Families Across Rhode Island

*Valencia III*

- **Christine McGrane, PhD, RN, CNE** • *Clinical Assistant Professor, College of Nursing, University of Rhode Island, Exeter, RI*

The Rhode Island Lifespan Respite Care Program assessed and acted upon the increasing need for group respite services, particularly on the weekends, and across all ages, as well as the students' willingness to volunteer their time in this endeavor. We have set our sights on meeting the respite needs of family caregivers closer to their homes through a networking process with parent advocates and special interest groups, guiding us toward the next step of satellite solutions.



**ENGAGE**

## Engaging Caregivers Through Co-located Services

*Mediterranean V*

- **Lisa Felci Jimenez, LSW, RN** • *Director of Clinical Services, Mystic Valley Elder Services, Malden, MA*
- **Lisa Beauregard, PhD** • *Director of Quality and Evaluation, Mystic Valley Elder Services, Malden, MA*

Mystic Valley Elder Services is providing co-located services for caregivers and care recipients funded through a grant provided by the Massachusetts Executive Office of Elder Affairs. Co-located services offer an opportunity for caregivers to engage with their care recipient in programming that allows for them to fall back into their previous roles as partners, child-parent or friends and participate in an activity that sparks joy.



**DISCOVER**

## Understanding Caregivers Experiences with Respite Care: Insights from a Nebraska Statewide Survey

*Mediterranean IV*

- **Renee Paulin, MSN, RN, CPN, CWO CN** • *Assistant Director, Continuing InterProfessional Development and Innovation, Wound Treatment Associate Course Coordinator, University of Nebraska Medical Center (UNMC), College of Nursing, Omaha, NE*
- **Sarah Swanson, MPH** • *Assistant Professor, UNMC Munroe-Meyer Institute (MMI), Omaha, NE*
- **Kim Falk, BSBA** • *Program Manager, UNMC Munroe-Meyer Institute (MMI), Omaha, NE*

This session presents findings from a statewide survey in Nebraska assessing caregivers access to respite care services and the impact of respite on well-being. The presentation will highlight barriers such as workforce shortages, caregiver trust, and geographic disparities, and propose strategies for improving access. These results provide insights into caregiver needs and lead to solutions that can be applied nationally to support families caring for children with disabilities.





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## Wisconsin's Advancing State Implementation of the National Strategy to Support Family Caregivers Grant Overview

*Mediterranean VI*

- **Lynn Gall** • *Manager of Family Caregiver Support and Lifespan Respite Programs, Bureau of Aging and Disability Resources, Wisconsin Department of Health Services, Madison, WI*
- **Leslie Thede** • *Program Manager, Respite Care Association of Wisconsin (RCAW), Appleton, WI*
- **Rachel Watkins-Petersen** • *Assistant Director, Respite Care Association of Wisconsin, Appleton, WI*

We will explore how Wisconsin utilizes a comprehensive framework to develop, test, and scale models aligning with four of The Strategy's five goals. The session will highlight key implementation strategies, including building cross-sector collaborations and designing tailored support systems for diverse caregiver populations. We will discuss methods for measuring the project's impact and documenting progress to ensure Wisconsin's efforts contribute meaningfully to advancing The Strategy's goals and providing lasting support for family caregivers.



**LAUNCH**

## Helping Kinship Families Thrive with Respite Services

*Valencia II*

- **Ana Beltran, JD** • *Director, Grandfamilies & Kinship Support Network/Generations United, Washington, D.C.*

Across the U.S. there are about 2.5 million children being raised by a grandparent, other relative, or close family friend. Kinship families have unique challenges that, if not addressed, can threaten a family's stability and potentially result in a child's placement in foster care with someone unfamiliar. Respite services support kin caregivers and keep families together. Learn promising practices that are being used around the country to provide respite services that help kinship families thrive.

**11:15 – 11:30 AM Break**



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11:30 AM – 12:30 PM

## Breakout Session E



**EXPLORE**

### Explore Different Statewide Respite Registries and Learn Steps on How to Implement in Your State

*Mediterranean II*

- **Lisa Schneider** • Executive Director, Respite Care Association of Wisconsin, Appleton, WI
- **Adrienne Smith** • President and CEO, Founder, New Mexico Caregivers Coalition, Bernalillo, NM
- **Sharon Cackett** • Assistant Director, NYS Caregiving and Respite Coalition, Rochester, NY

This session will provide a comprehensive overview of Respite Care Provider Registries, covering their function, purpose, importance, and implementation strategies. Attendees will hear insights from three organizations: the Respite Care Association of Wisconsin, New Mexico Caregiver Coalition, and the New York State Caregiving and Respite Coalition – each at different stages in their registry implementation. These three state representatives will discuss the strategies they employed to tackle challenges associated with implementing a statewide respite registry. Presenters will outline the measures taken to mitigate liability and risk concerns, as well as examine the pros and cons of conducting background checks, providing valuable insights to assist your organization in moving forward with a statewide respite registry. The session will include an interactive Q&A segment.



**EXPLORE**

### Redefining Respite: Caregiver Connections in Low-Resource Settings

*Valencia III*

- **Sarah Toevs, PhD** • Idaho Caregiver Alliance and Professor Emeritus, School of Public and Population Health, Boise State University, Boise, ID

The National Strategy to Support Family Caregivers defines respite as “any activity that provides the caregiver with a meaningful break.” While this broad definition is somewhat controversial, there is consensus on the desired outcomes of respite. The processes, outcomes, and lessons learned from implementation of family caregiver intervention in a rural state and the question of whether a telephonically delivered program with evidence of improving caregiver quality of life and capacity provides a meaningful break will be explored.



**LAUNCH**

### Charting the LifeCourse: A Person-Centered Approach for Respite Planning

*Mediterranean V*

- **Jane St. John** • Lead Production Development Specialist, LifeCourse Nexus, University of Missouri-Kansas City, MO

Hear how Charting the LifeCourse (CtLC) can enhance respite planning and outcomes for the person and the family. The CtLC person-centered planning process and tools are being used around the country to support good lives for any age or any diagnosis.



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## Center for Dementia Respite Innovation Application Lessons Learned

*Mediterranean IV*

- **Isabella Marini** • Associate Director, Center for Dementia Respite Innovation, Alzheimer’s Association, Chicago, IL
- **Sara Maloney** • Program Director, Center for Dementia Respite Innovation, USAgIng, Washington, D.C.
- **Katie Ballard** • Program Manager, Center for Dementia Respite Innovation, USAgIng, Washington, D.C.

The Alzheimer’s Association Center for Dementia Respite Innovation (CDRI) funds new respite care innovation projects nationwide. Over the course of five years, the CDRI will award \$20 million in competitive grants to respite care providers to increase the availability and to improve the delivery of person-centered dementia care focusing on innovation, collaboration, accessibility, affordability and sustainability. Presenters will share lessons learned from the first application cycle as organizations prepare to apply in year 2.



**DISCOVER**

## ARCH’s Respite Research Initiative: Measuring the Value of Respite

*Mediterranean I*

- **Kim Whitmore, PhD, RN** • ARCH Consultant and Assistant Professor, Marquette University College of Nursing, Milwaukee, WI

Through its decade long Respite Research Initiative, the ARCH National Respite Network and Resource Center undertook activities to expand and strengthen opportunities for respite research. ARCH convened the Committee for Advancement of Respite Research in 2020 to continue to advance a respite research agenda and held a Respite Research Summit in 2024 to highlight CARR’s capstone work – the Value of Respite Model and Recommended Common Data Elements (CDEs) for Respite Research. In this session, Dr. Kim Whitmore, CARR facilitator, will describe the model and CDEs, summarize the major findings from the Respite Research Summit, and share next steps for building an evidence-base for respite care.





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**REFUEL**  
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Networking and  
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**LAUNCH**  
Innovative Services  
and Systems



**PROPEL**  
the Respite  
Workforce



**NAVIGATE**  
Support for Working  
Caregivers



**ENGAGE**  
Family Caregivers



**EXPLORE**  
the Universe of  
Lifespan Respite



**LAUNCH**

## Respite Sibshops and Sibling Camp: Inclusive Models to Support the Family as a Whole

*Mediterranean III*

- **Samantha Basave** • *Oklahoma Sibling Support Coordinator, Sooner SUCCESS, Oklahoma City, OK*
- **Aietah Stephens, MS** • *Executive Director, Sooner SUCCESS, Oklahoma City, OK*

This session will explore evidence-based curricula and approaches to supporting families of children with and without disabilities, such as Respite Sibshops and Sibling Camp, emphasizing the importance of fostering strong family relationships. It will address the emotional, social/psychological impacts on people with disabilities, caregivers, and siblings. Attendees will learn strategies to build caregiver trust in respite, promote resilience in individuals with disabilities, and create supportive networks for siblings.



**PROPEL**

## Skilled, Competent, and Confident: What Does it Mean to Build a Respite Workforce for Children with Medical Complexity?

*Mediterranean VI*

- **Emily Davidson, MD, MPH, RYT** • *Attending Physician, Boston Children's Hospital, Boston, MA*
- **Sarah Wells, MSN, RN, CPN, CWOCN** • *Clinical Nurse Specialist, Boston Children's Hospital, Boston, MA*

Scholar Provided In-home Respite Novel Training (SPRINT) is a project designed to address workforce shortages for home care and respite for children with medical complexity. This seminar will describe the SPRINT model for training nursing students, share results of SPRINT implementation, and demonstrate new online, self-paced respite training modules designed to introduce a variety of learners to respite for children with medical complexity.



**LAUNCH**

## Empowering Family Caregivers: Innovative Respite Voucher Programs for Enhanced Support

*Valencia II*

- **Julie Lowenthal** • *Program and Advocacy Specialist, Ageways Nonprofit Senior Services, Southfield, MI*

The Caregiver Respite Voucher Program supports family caregivers by offering temporary relief and reducing stress. Modeled after the Federal Lifespan Respite Care Act, the program distributes vouchers to eligible caregivers in southeastern Michigan. It improves caregiver well-being, enhances care for older adults, and promotes a sustainable caregiving environment. The presentation will cover the program's structure, impact, and sustainability, highlighting its role in addressing the caregiver crisis and supporting vulnerable populations.

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## Thursday Afternoon, April 3, 2025

**12:30 – 1:00 PM Break**

**1:00 – 2:45 PM LUNCH and CLOSING PLENARY SESSION**

*Mediterranean Ballroom III and IV*

### PANEL DISCUSSION

#### *Amplifying Family Caregiver Voices*

This panel will offer an engaging opportunity to hear directly from family and friend caregivers, and those who work with caregivers, about the challenges they experience every day. Panelists will share the personal stories of caring for underserved, and sometimes even seemingly invisible, populations – young caregivers, Hispanic and African American families, medically complex children, and Veterans. Together they will explore how we can work together to amplify their voices and provide them with greater opportunities for respite and other supports.



MODERATOR

**Nick Nyberg**

*Programs and Planning Division Chief  
Alabama Department of Senior Services (ADSS)*

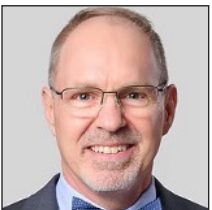
### PANELISTS



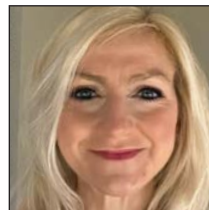
**Feylyn Mercedes Lewis, PhD**  
*Young Caregiver Advocate  
Assistant Dean of Student Affairs,  
Vanderbilt University School of  
Nursing, Nashville, TN*



**Maria Gutierrez**  
*Family Caregiver/Family Navigator,  
Auburn University Regional Autism  
Network, Auburn, AL*



**Jonathan Cottor, MBA, MPH**  
*Parent Caregiver  
Chief Executive Officer and Founder  
National Center for Pediatric  
Palliative Care Homes and  
Children's Respite Homes of  
America, Phoenix, AZ*



**Theresa Vollor, MSW, LICSW**  
*VA Caregiver Support Program  
Manager, Birmingham VA  
Healthcare System, Birmingham, AL*

**2:45 – 3:00 PM Wrap-Up and Conference End**

# Conference Exhibitors

**Alabama Council on Developmental Disabilities**

[acdd.org](http://acdd.org)

**Alabama Disabilities Advocacy Program (ADAP)**

[adap.ua.edu](http://adap.ua.edu)

**Alabama Head Injury Foundation**

[ahif.org](http://ahif.org)

**Alabama Lifespan Respite**

[alabamarespite.org](http://alabamarespite.org)

**Alzheimer's Association**

[alz.org](http://alz.org)

**CareAcademy**

[careacademy.com](http://careacademy.com)

**Grandfamilies & Kinship Support Network**

[GKSNetwork.org](http://GKSNetwork.org)

**Parkinson's Foundation**

[parkinson.org](http://parkinson.org)

**Respitrack/UCP Sacramento**

[respitrack.com](http://respitrack.com)

**SafeInHome**

[safeinhome.com](http://safeinhome.com)

**Sun Back Moon, LLC**

[sunbackmoon.com](http://sunbackmoon.com)

**TCARE**

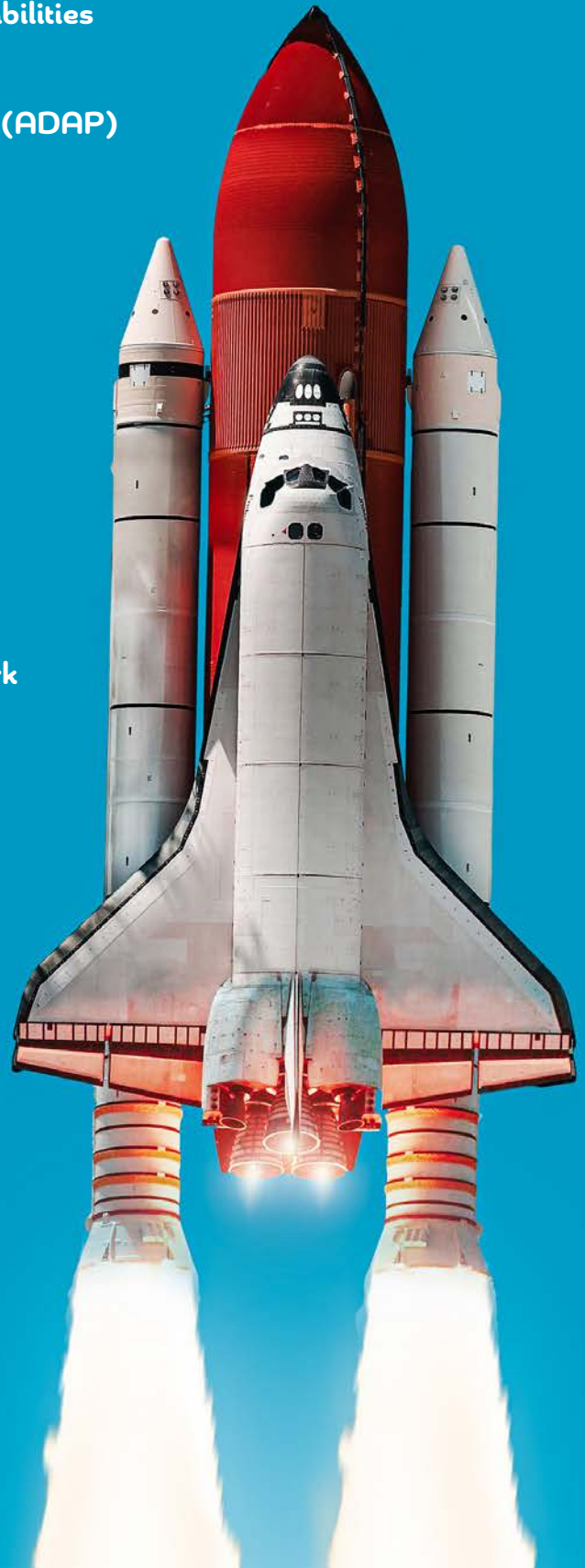
[tcare.ai](http://tcare.ai)

**UAH Regional Autism Network**

[mh.alabama.gov/aiacc/regional-autism-network](http://mh.alabama.gov/aiacc/regional-autism-network)

**UCP of Huntsville & Tennessee Valley**

[ucphuntsville.org](http://ucphuntsville.org)



# Schedule At-a-Glance

## Monday, March 31, 2025

6:00 – 8:00 pm ✦ Early Conference Registration  
6:00 – 8:00 pm ✦ Networking Reception for Lifespan Respite Grantees, Partners and Guests (by invitation only)

## Tuesday, April 1

8:00 – 9:00 am ✦ Registration and Breakfast for Lifespan Respite Grantee and Partner Learning Symposium Attendees  
9:00 am – 3:00 pm ✦ Lifespan Respite Grantee and Partner Learning Symposium (by invitation only)  
3:00 – 8:00 pm ✦ National Conference Registration  
6:00 – 8:00 pm ✦ National Respite Conference Welcome Reception

### RECOGNITION

ARCH 2025 Innovative and Exemplary Respite Services

## Wednesday, April 2 – Conference, Day 1

7:00 am – 5:00 pm ✦ Registration/Information Table  
7:30 – 9:00 am ✦ Breakfast  
9:00 – 10:30 am ✦ Opening Session and Welcome  
**Jill Kagan**, MPH, Director, ARCH National Respite Network and Resource Center  
**Cheryl Smith**, CEO, United Cerebral Palsy (UCP) Huntsville and Tennessee Valley  
**Darryle Powell**, MS, Chairman, Alabama Lifespan Respite Coalition, and Executive Director, Alabama Council for Developmental Disabilities

### KEYNOTE

**Kristin Scroggin**, Managing Partner and Lead Trainer, genWHY Communication Strategies, Huntsville, AL

10:30 – 11:00 am ✦ Break  
11:00 am – 12:00 pm ✦ Breakout Session A  
12:00 – 12:30 pm ✦ Break  
12:30 – 2:15 pm ✦ Luncheon Plenary

### SCREENING

PBS Documentary Caregiving (30-minute preview)

### PANEL DISCUSSION

MODERATOR: **Marcus R. Escobedo**, MPA, Communications and Senior Program Officer, The John A. Hartford Foundation

PANELISTS:

**Josh Carter**, Grandchild of President Jimmy Carter and Rosalynn Carter and Spokesman for the Rosalynn Carter Institute for Caregivers

**Lynnette Canedy**, Family Caregiver and 2023 Elizabeth Dole Fellow

**Christopher Durrance**, Director and Senior Producer of Caregiving, Ark Media

**Tom Chido**, Executive Producer of Caregiving and Special Projects, National Productions, WETA/PBS

2:15 – 2:45 pm ✦ Break  
2:45 – 3:45 pm ✦ Breakout Session B  
3:45 – 4:00 pm ✦ Break  
4:00 – 5:00 pm ✦ Breakout Session C  
Evening ✦ Dinner on your own

## Thursday, April 3 – Conference, Day 2

7:30 am – 3:00 pm ✦ Registration/Information Table  
7:30 – 8:30 am ✦ Breakfast  
8:30 – 9:45 am ✦ Morning Plenary Session – Welcome and Announcements

### KEYNOTE

National Strategy to Support Family Caregivers: Progress and Next Steps

**Kari Benson**, Deputy Assistant Secretary for Aging, Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Service (Invited)

**Jonathan Cottor**, MBA, MPH, Co-chair, RAISE Family Caregiving Advisory Council; Chief Executive Officer and Founder, National Center for Pediatric Palliative Care Homes and Children's Respite Homes of America

9:45 – 10:15 am ✦ Break  
10:15 – 11:15 am ✦ Breakout Session D  
11:15 – 11:30 am ✦ Break  
11:30 am – 12:30 pm ✦ Breakout Session E  
12:30 – 1:00 pm ✦ Break  
1:00 – 2:45 pm ✦ Luncheon Plenary

### CLOSING PANEL

Amplifying Family Caregiver Voices

MODERATOR: **Nick Nyberg**, Programs and Planning Division Chief, Alabama Department of Senior Services

PANELISTS:

**Feylyn Mercedes Lewis**, PhD, Assistant Dean of Student Affairs, Vanderbilt University School of Nursing and Young Caregiver Advocate

**Jonathan Cottor**, Parent and Chief Executive Officer and Founder, National Center for Pediatric Palliative Care Homes and Children's Respite Homes of America

**Maria Gutierrez**, Family Caregiver and Family Navigator, Auburn University Regional Autism Network

**Theresa Vollar**, MSW, LICSW, VA Caregiver Support Program Manager, Birmingham VA Healthcare System

2:45 – 3:00 pm ✦ Wrap Up and Conference End

Free Wifi available: *Westin\_Guest* (no password required)

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