CONGRATULATIONS TO THE WEST FALLS CENTER FOR THE ARTS’ MUSICAL MEMORIES CAFÉS FOR THEIR WELL-DESERVED RECOGNITION FROM THE ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER AS AN INNOVATIVE AND EXEMPLARY RESPITE SERVICE!

The Ralph C. Wilson, Jr. Foundation is proud to support such groundbreaking work through our partnership with Exhale, The Family Caregiver Initiative.

Together, let’s continue spreading the transformative impact of memory cafés and respite for caregivers far and wide.

RW
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exhale
THE FAMILY CAREGIVER INITIATIVE
Welcome to Albany and to the 2024 National Lifespan Respite Conference!

In 2022, the Administration for Community Living released the first-ever National Strategy to Support Family Caregivers. In keeping with our collective commitment to advance the recommended respite actions in the National Strategy, the theme for the conference is RAISE the Bar for Respite – Strategies to strengthen family caregivers.

The conference will provide the space and energy to lift up best practices in respite care; elevate innovative public and private sector approaches to expand support for working caregivers; escalate new strategies to grow respite capacity to meet the ever-increasing need; step up action to address the direct care workforce crisis; and increase our commitment to person and family-centered respite services for the nation’s more than 53 million 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 – new respite voucher programs, exemplary voluntary and faith-based respite initiatives, innovative respite and caregiver support programs sparked by state mini grants, easier access to respite services, and hundreds of new respite workers and volunteers trained from coast to coast.

Here in New York, the New York State Caregiving and Respite Coalition, in partnership with the New York State Office for the Aging, is forging new innovations for respite and caregiver support every day, through the use of AmeriCorps Seniors volunteers, a new Caregiver Wellness and Respite Center, an expanded respite voucher program, active engagement with the State Master Plan for Aging, and more. They have used their Lifespan Respite grant funds to leverage additional state and federal funds to train new providers, ignite innovation through community respite initiatives, engage diverse communities, support working caregivers, and most importantly, share their successes and expertise with the rest of the national respite network.

RAISE the Bar for Respite 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. We will rethink how we provide person and family-centered respite, how we reach working caregivers and families from diverse communities, and how we address the ever-growing need for meaningful respite and caregiver supports at both state and national levels.

Take advantage of everything the conference and Albany have to offer and let’s RAISE the Bar for Respite together.

Your 2024 National Lifespan Respite Conference Hosts:
 Commitment to Diversity, Equity, and Inclusion
The National Lifespan Respite Conference is intended to foster the exchange of diverse ideas and perspectives by providing participants with an opportunity to present their lived experiences, best practices, and research findings, establish/renew collaborations, and learn, teach, and network with a community of individuals interested in respite care. The ARCH National Respite Network and the New York State Caregiving and Respite Coalition are committed to creating a safe, equitable, and inclusive environment for all participants, including staff and vendors. Discrimination on the basis of gender or gender identity, sexual orientation, age, disability, physical appearance, race, religion, national origin, or ethnicity will not be tolerated. Participants are expected to adhere to these principles and respect the rights of others. Participants should report any behavior inconsistent with the principles outlined here to info@archrespite.org.

Albany
Albany has a rich history dating back more than 400 years. When Henry Hudson arrived in 1609, the area was already home to the Haudenosaunee (Iroquois) and the Dutch had established a trading post.

In 1797, Albany became the official capital of New York State. Since then, Albany has been a center for banking, railroads, and international trade. Four New York state governors went on to become President of the United States.

Construction on the New York State Capitol building began in 1867 and took over 30 years to complete at a cost of more than $25 million. The New York State Capitol has 17 steps approaching its western entrance and 77 steps approaching its eastern entrance in honor of the year 1777, when New York replaced its colonial government with the current state government.

The Empire State Plaza which sits on 98 acres with more than 900,000 cubic yards of concrete, and 232,00 tons of steel cost $1.7 billion to build. It interconnects eleven buildings including the Capitol and State Museum.

The telegraph, electric motor, and celluloid plastic were all pioneered here. Albany was also the point of origin for the first long-distance airplane flight and the first passenger railroad.
Conference Sponsors

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OKCares

Share your conference pictures and highlights on LinkedIn, Instagram, X, and Facebook with #RAISErespite.
The Hilton Albany hotel is in the Capital District of downtown Albany, a five-minute walk from MVP Arena. It is less than eight miles from Albany Airport and within two miles of the Amtrak station. Some rooms offer views of the Hudson River and New York State Capitol.
Uplifting family caregivers—

We’re building a Lifespan Respite Care System.
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.

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

to the Lifespan Respite Technical Assistance and Resource Center
2020-2025

State Lifespan Respite Representatives

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Oklahoma Department of Human Services

Aleatha Dickerson
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National Association of State Head Injury Administrators

Laura Weidner
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Mike Wittke
National Alliance for Caregiving

William Zagorski
National Adult Day Services Association
Innovative and Exemplary Respite Services

The ARCH National Respite Network and Resource Center is proud to recognize Innovative and Exemplary Respite Services for 2024.

ARCH recognizes four Innovative and Exemplary respite services 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.

C.H.A.I. (Caregiving Helping Aid Initiative)

C.H.A.I. (Caregiving Helping Aid Initiative), is a Chaldean Community Foundation (CCF) program. Located in Sterling Heights, Michigan, C.H.A.I. strengthens the CCF’s mission by continuing to improve the stability, health, and wellness of new Americans including refugees, immigrants, and vulnerable families. C.H.A.I. multilingual staff works to develop trust with caregivers over time. Connecting the caregiver through inclusive community supports, wrap-around social services, and ongoing education for the caring of loved ones with intellectual and/or developmental disabilities, builds trust over time. Caregivers can also find self-care through social opportunities, support for individuals with dementia, wellness initiatives, recreation and a shared-respite model that continues to evolve. Website: chaldeanfoundation.org/behavioral-health
Musical Memories Café
The Musical Memories Café, located in rural West Falls, New York, and nearby communities, provides shared respite experiences for persons with Alzheimer’s Disease and dementias and their caregivers, and other physically or socially isolated adults. Musical Memories Cafés offer regularly scheduled live music with local musicians and communal meals at community venues. Strong evaluation data collected by the Musical Memories Café program shows positive outcomes including reduced caregiver stress and improved caregiver-care recipient relationships. Website: westfallsartcenter.org/memory-cafe167513f0

Saint Louis Crisis Nursery
The Saint Louis Crisis Nursery has provided trauma-responsive 24/7/365 emergency respite care services for children in the Greater St. Louis, Missouri region for nearly 40 years, and has since grown to include five 24-hour Nursery locations delivering its nationally and internationally replicated child abuse and neglect prevention programming to thousands of local families annually. Core services include 24/7 crisis intervention and emergency respite care for children as well as wrap around support for families at high risk of abuse or neglect. Annually, greater than 99% of the 4,000+ children served remain free from abuse or neglect, 95% of parents report decreased stress levels, and 95% of families meet safety and stability goals. Website: crisisnurserykids.org

Will’s House
Will’s House, located in Tulsa, Oklahoma, was designed to provide customized respite care, including medical needs care, short-term, long-term, and emergency respite, to support families caring for children and young adults with disabilities. Will’s House is also a specialized foster care placement for the state of Oklahoma. Will’s House, a non-profit organization, is also designed to ease the financial strain families may experience obtaining respite care by offering “pay what you can” services, but no families are turned away from services for financial reasons. Of the families using Will’s House respite services, 98% return for subsequent respite services. Website: willshousetulsa.org

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $1,647,597 with 75 percentage funded by ACL/HHS and $549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.
Conference Tracks

Breakout session topics cross over multiple disciplines, reflecting the wide range of respite options required and used by caregivers across the lifespan. Sessions are grouped into one of five topical tracks or the Lifespan Respite Track described below. Presenters will show how their work RAISES the Bar for Respite and aligns with National Strategy Goals.

The National Strategy to Support Family Caregivers proposes five main goals:

- **GOAL 1**: Increase awareness and outreach
- **GOAL 2**: Build partnerships and engagement
- **GOAL 3**: Strengthen services and supports
- **GOAL 4**: Ensure financial and workplace security
- **GOAL 5**: Expand data, research, and evidence-based practices

The following presentation tracks align with the National Strategy’s five goals and RAISE the Bar for Respite:

**Research and Evaluate**

*Aligns with National Strategy Goal 5*

A solid evidence-base for respite is essential to make the case for respite availability and funding. 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 the respite we provide. This track will present findings from evaluations of lifespan respite activities, respite models, alternative respite and support interventions, strategies for meaningful performance measurement, and practices to assure diversity, equity, inclusion, and accessibility in all research and evaluation efforts.

**Advocate, Network and Sustain**

*Aligns with National Strategy Goal 2*

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, especially with diverse, marginalized and underresourced groups. Presentations may explore financing strategies for sustainability, unique partnerships, successful coalitions, legislative advocacy, and other elevated contexts for providing, promoting, and sustaining respite.
Innovate Services, Systems and Direct Care Workforce Strategies  
*Aligns with National Strategy Goal 3*

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

Presentations will also focus 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, qualified, and culturally and linguistically competent respite providers and care options.

Support Working Caregivers  
*Aligns with National Strategy Goal 4*

A significant majority of family caregivers, at least 60 percent, are in the labor force. A more responsive and supportive workplace is needed to enable them to continue to work and provide care. Not only are the health and financial wellbeing 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 explores successful strategies to ensure respite and other caregiver supports are available and accessible to working caregivers.

Educate and Engage Family Caregivers  
*Aligns with National Strategy Goal 1*

This track is geared toward family caregivers and those who work with family caregivers who want to learn more about successful caregiving strategies, meaningful respite, resources that support caregivers, and impactful stories about the benefits of respite and caregiver wellness programs. Family caregivers will also share what they imagine their dream respite might be.

Service providers will share how they engage family caregivers to use respite services as well as participate in respite and caregiving coalitions, planning, advocacy and evaluation. Successful public awareness campaigns, new messaging techniques and technologies, and strategies to engage diverse and marginalized communities are featured.

**RAISE the Lifespan Respite Track**

*Aligns with all five National Strategy goals*

This track will interest all attendees because it highlights service delivery and systems change grant activities undertaken by State Lifespan Respite grantees and State Respite Coalition partners. 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 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.

Current and former Lifespan Respite grantees and their partners will describe best practices, program successes, and challenges experienced in their Lifespan Respite grant implementation or coalition activities.
Conference Schedule

Monday Evening, May 20, 2024

6:00 – 8:00 PM  Early Registration  Gallery
7:00 – 8:00 PM  Networking Reception for Lifespan Respite Grantees, Partners, and Guests  Kelsey’s  (by invitation only)

Tuesday, May 21, 2024

8:00 – 9:00 AM  Registration and Breakfast for Lifespan Respite Grantee and Partner Learning Symposium Attendees  Kelsey’s
9:00 AM – 4:00 PM  Lifespan Respite Grantee and Partner Learning Symposium  Kelsey’s  (by invitation only)

Tuesday Evening, May 21, 2024

3:00 – 8:00 PM  National Conference Registration  Gallery
6:00 – 9:00 PM  OPENING SESSION and WELCOME DINNER  Governor’s Ballroom

KEYNOTE PRESENTATION

Jason Resendez • President and CEO
National Alliance for Caregiving

Meeting the Diverse Needs of Family Caregivers in Implementing the National Strategy to Support Family Caregivers
RECOGNITION CEREMONY

ARCH 2024 Innovative and Exemplary Respite Services

PRESENTORS: Casandra Firman and Susan Janko Summers
ARCH National Respite Network and Resource Center

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

• Molly Brown • Chief Executive Officer, Saint Louis Crisis Nursery, St. Louis, MO
• Jeanette O’Hara • Founder, Will’s House, Tulsa, OK
• Carolyn Panzica • Lead Artist, Musical Memories Café, West Falls Center for the Arts, West Falls, NY
• Jacqueline Raxter • Behavioral Health Program Manager, C.H.A.I. (Caregiving Helping Aid Initiative), Chaldean Community Foundation (CCF), Sterling Heights, MI

Wednesday Morning, May 22, 2024

7:30 AM – 5:00 PM Registration and Information Table

7:30 – 9:00 AM Breakfast

9:00 – 10:30 AM MORNING PLENARY SESSION and WELCOME

Presentation: Jill Kagan • ARCH National Respite Network and Resource Center
Presentation: Doris Green • New York State Caregiving and Respite Coalition
Presentation: Greg Olsen • Acting Director, New York State Office for the Aging

WELCOME VIDEO

Alison Barkoff • Performing the duties of the ACL Administrator and Assistant Secretary for Aging, Administration for Community Living, U.S. Department of Health and Human Services

KEYNOTE PRESENTATION

Greg Link • Director, Office of Supportive and Caregiver Services Administration for Community Living, Administration on Aging, U.S. Department of Health and Human Services

Raising the Respite Bar: The National Strategy to Support Family Caregivers as a Leadership Framework
10:30 – 11:00 AM  |  Break

11:00 AM – 12:00 PM  |  BREAKOUT SESSION A

**Exhale – The Family Caregiver Initiative: Overview, Multisite Evaluation and a Case Study of Innovative Respite Programming**  
*Governor’s Ballroom E*

- **John Tyler** • *Senior Philanthropic Advisor, The Philanthropic Initiative (TPI), Boston, MA*
- **Linda Weiss** • *Senior Researcher, Center for Evaluation and Applied Research, The New York Academy of Medicine, New York, NY*
- **Ann Battaglia** • *Chief Executive Officer, Healthy Community Alliance, Gowanda, NY*
- **Ashley Conti** • *Director of Programs, Healthy Community Alliance, Gowanda, NY*

Exhale, The Family Caregiver Initiative, supports innovation and expansion of respite services for caregivers of older adults. Exhale provides project development and implementation funding; a learning community; and assistance in creative problem solving, evaluation, communications, and sustainability. Exhale includes 16 projects in western New York and southeast Michigan. Project models are diverse as re-imagined respite can take many forms; examples include technology supports (home cameras, tablets), wellness activities, and musical programming for caregivers and carees.

**New York State’s Caregiver Wellness and Respite Center: Steering the Wheel towards a Hub and Spokes Model**  
*Capitol AB*

- **Abbey Derepentigny** • *Caregiver Support Program Assistant Director, New York State Office for the Aging, Albany, NY*
- **Mikaela Oliver** • *Regional Care Navigator, Alzheimer’s Disease Caregiver Support Initiative and Caregiver and Wellness Respite Center, Plattsburgh, NY*
- **Linda Miller** • *Vice President of Government Programs, TCARE, St Louis, MO*

Tailored Caregiver Assessment and Referral (TCARE) is a care management and planning protocol designed to support family members who are providing unpaid care. When providers identify family caregivers and ask them about their needs, preferences, and willingness and ability to provide support, they gain a better understanding. Learn about the Caregiver Wellness and Respite Center (CWRC) and how its case managers use TCARE and other services and supports to support autonomy and well-being of caregivers.
**Release of the Respite Provider Recruitment and Training Replication Toolkit**

**State AB**

- **Kim Whitmore** • PhD, RN, CPN, College of Nursing, Marquette University, Milwaukee, WI
- **Lisa Schneider** • Executive Director, Respite Care Association of Wisconsin, Appleton, WI

ARCH National Respite Network and Resource Center, in partnership with the National Academy for State Health Policy and the Respite Care Association of Wisconsin, piloted a competency-based respite provider recruitment and training in ten states. As a result of the pilot, this training is now available to all states. In this session, learn about the results of the pilot and how to build a training and recruitment program for respite providers in your state or community by accessing the new Replication Toolkit.

**Why Doesn’t My Family Help?**

**Anteroom**

- **Mary Berk** • Family Mediator, New York State Caregiving and Respite Coalition (NYSCRC), Rochester, NY

Observe a mediation session among family members who have lots of excuses why they are unable to provide respite and other types of support to the primary caregiver and care receiver. As caregivers, we expect that our family members should be willing to help us when we ask. When they fail to do so we tell ourselves that they are selfish, spoiled, indifferent, uncaring, or worse. You may be surprised as you listen to their side of the story.

**Evolution of the Crisis Nursery: From Emergency Childcare to Family Preservation Program**

**Empire AB**

- **Natalie Leek** • President and CEO, Providence House, Cleveland, OH
- **Amy Mills** • Center for Crisis Nurseries Manager, Providence House, Cleveland, OH

The Providence House Family Preservation Crisis Nursery Model keeps kids safe and families together by embracing them with support to enhance stability that strengthens communities. Participants will learn how their free, voluntary, noncustodial 24/7 crisis respite shelter for children, blended with trauma-informed Family Preservation services for parents/guardians and range of community-based services has evolved into a multi-generational, nationally recognized program that supports crisis intervention, family preservation, hope, and healing for the entire family.
Attracting Attention for Respite from Public Officials

- Adrienne Smith • President and CEO, New Mexico Caregivers Coalition, Bernalillo, NM

This session will explore strategies for building public support for your respite care program in ways that make use of current resources and that set the stage for future state and local funding. This session will describe the various collaborative partnerships and public awareness campaigns that a statewide coalition is using to build support for respite care provider training, recruitment and retention.

A Lawyer? How Adding a Novel Partner to Your Team Can Improve Outcomes for Caregivers

- Amanda Nobrega • Vice President of Programs, Upstate New York, Alzheimer’s Association, Buffalo, NY
- Daniel Geyer • Staff Attorney, Center for Elder Law and Justice, Buffalo, NY

Join Alzheimer’s Association, Western New York Chapter (AAWNY) and Center for Elder Law and Justice (CELJ) as they discuss their innovative partnership to effectively serve caregivers of those living with Alzheimer’s disease and dementia. AAWNY and CELJ will explain their service model, identifying gaps in services, and how adding a novel partner can fill these needs. Also learn how to replicate this model for use across different populations, harmonize collective goals, and improve outcomes for caregivers.

What’s Your Story? Helping Family Caregivers and Stakeholders Develop Powerful Personal Narratives to Advance Respite Awareness

- Mary Jo Alimena Caruso, M.Ed. • T/TA Coordinator, FRIENDS National Center for Community-Based Child Abuse Prevention (CBCAP), Baden, PA
- Vadonna Williams • Parent Advisory Council, FRIENDS National Center for CBCAP, Northport, AL
- Eileen Graham • Parent Advisory Council, FRIENDS National Center for CBCAP, McDouough, GA

Storytelling is one of the most valuable resources in our toolbox. Our personal stories, developed and told in our authentic voices, become powerful and persuasive tools for building understanding and action with the audience.

This skill-building workshop will provide storytelling tools to elevate respite/caregiver issues in your community. Learn to craft and share a meaningful and credible story, raise respite awareness, and inspire people to act and bring about change. What’s your story?

12:00 – 12:15 PM Break
Wednesday Afternoon, May 22, 2024

12:15 – 2:00 PM  LUNCHEON PLENARY SESSION  Governor’s Ballroom

KEYNOTE PRESENTATION
Alexandra Drane • Co-Founder and CEO
ARCHANGELS

Any Care Counts
to Your Top, Bottom, and Heart-Line

2:00 – 2:15 PM  Break

2:15 – 3:15 PM  BREAKOUT SESSION B

SHARED SESSION  Chambers

SESSION 1: Stress Reduction Through a Group Respite Intervention for Parents of Children with Special Needs

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

The challenges and stress of providing care at home can impact both the child’s and family’s environment and quality of life. A 12-week group respite program during the spring of 2023 was provided on a 1:1 ratio by nursing and PT student volunteers. Using a mixed method approach, this study examined the impact of a specific intervention, a group respite program, on caregiver stress among family caregivers (parents) of children with special needs.

SESSION 2: Respite Experiences of Latinx Families of Children with Special Healthcare Needs

• Kim Whitmore, PhD, RN, CPN • College of Nursing, Marquette University, Milwaukee, WI

This presentation will highlight a study of the respite experience of Latinx families of children with special healthcare needs. The Latinx Respite Survey involved Latinx parents of children with special healthcare needs (CSHCN) completing an anonymous survey that included questions about the CSHCN, their experience with respite care, as well as the Family APGAR, Perceived Stress Scale (PSS-10), and the Global Family Quality of Life Scale. Participants were also invited to schedule an interview to share more about their experience.
Empowering Caregivers Navigating the Future of Respite through Massachusetts’ 40 Innovation Grants

Kelsey’s

- Amy Nazaire • Department of Developmental Services – Northeast Region, Hathorne, MA
- Sarah Harrigan, MPA • Senior Consultant, Public Consulting Group, LLC, Providence, RI

This presentation highlights the Massachusetts initiative to fund 40 innovative respite projects that emphasize the experience of caregivers. By capturing the voices of caregivers, conducting data-driven assessments, and fostering collaboration, this initiative seeks to transform the landscape of caregiver support, ensuring better well-being for caregivers and improved services for those in need.

Employers Raising the Bar for Working Caregivers

Governor’s Ballroom

- Harriet Redman • Co-chair of Engaging Employers Workgroup, Wisconsin Family and Caregiver Support Alliance, Appleton, WI
- Lynn Gall • Manager, Family Caregiver Support and Lifespan Respite Programs, Wisconsin Department of Health Services, Madison, WI

This interactive presentation will briefly present a study of Wisconsin employers and employed caregivers. Then attendees will learn specific strategies some employers are using to raise the bar of benefits and support to attract and retain working caregivers. The Wisconsin Family and Caregiver Support Alliance (WFACSA) Human Resources Care Kit will be introduced to help social service providers, human resource professionals, and others create successful strategies to help engage employers in supporting working caregivers.

Recognizing LGBTQ+ Families of Choice – When Love Surpasses Blood

Empire AB

- Crystal Collette • Assistant Director for Special Projects, New York State Office for the Aging, Albany, NY

This session will focus on understanding the lived experiences of family caregivers who support older adults from the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) community and/or identify as LGBTQ+ themselves. Respite providers, professionals and institutions need to collaborate with LGBTQ+ communities to provide meaningful support and ultimately begin to build trust and understanding. This session will aid you in developing a personal action plan to better support and serve the LGBTQ+ community.
Central to South Carolina’s efforts to build a Coordinated Lifespan Respite System have been expanding partnerships across the lifespan and coordinating systems and services to “Raise the Bar for Respite” to support family caregivers. Presenters will discuss four major strategies and accomplishments to coordinate respite systems and services that have positioned South Carolina to implement the National Strategy to Support Family Caregivers and address its main goals.

The “Sibling Sandwich” describes the unique experience of caregiving responsibilities for both siblings with disabilities and aging parents. Through storytelling and group conversation, this session seeks to support sibling caregivers by building community, prioritizing self-care, and educating policymakers.

For the past two years, the State of North Carolina through the Lifespan Respite Grant has been working to create a statewide volunteer caregiver respite consortium to innovate, promote, and increase respite capacity across the state. While we have achieved some successes, there have also been challenges. People who attend will get a “how to” guide to create a consortium in your area. If you have one, we welcome you to be part of the discussion and share your experiences and stories.

3:15 – 3:45PM Break
BREAKOUT SESSION C

Caregiving Youth Need Respite Too!  

Chambers

- Connie Siskowski  
  President and Founder, American Association of Caregiving Youth (AACY), Boca Raton, FL

Learn about the growing population of children who are primary or secondary family caregivers, the types of circumstances that demand their participation, and the need for innovation in providing support for child caregivers. Explore solutions for them academically and personally, including their need for a regular break from their responsibilities.

Innovations and Scaling in Respite Services Delivery and Outreach  

Capitol AB

- Susan Reinhard, PhD  
  Senior Vice President and Director, AARP Public Policy Institute, Washington, DC
- Brandon Flinn  
  Senior Policy Advisor, AARP Public Policy Institute, Washington, DC

This session provides an overview of policy and programs that address respite needs and spotlight innovative, locally-driven models that make real differences within communities. We will also discuss ways to scale innovations, leverage outreach, and highlight the role of stakeholders across fields.

Albany Guardian Society improves the lives of older adults & caregivers. Each year offering 150+ free classes & programs.

To learn more, go to: www.albanyguardiansociety.org

We make respite happen!

RCAW  
Respite Care Association of Wisconsin

www.respitecarewi.org info@respitecarewi.org

Proud Silver Sponsor of the 2024 National Lifespan Respite Conference

May 21- May 23, 2024 | Albany, New York
SHARED SESSION

SESSION 1: Priority Needs of Texas Family Caregivers: Findings from a 2023 Mixed-Method Study

- Nandita Chaudhuri, PhD • Research Scientist, Public Policy Research Institute, Texas A&M University, College Station, TX

This presentation from the Public Policy Research Institute at Texas A&M highlights key barriers to respite service use by family caregivers, respite providers, and other respite stakeholders in Texas. Funded by Texas Health and Human Services Commission (HHSC), the 2023 multi-stage needs assessment study findings reflect on critical perspectives of barriers and hindrances from Texas family caregivers of all ages and backgrounds. Lessons inform existing initiatives to motivate utilization of respite services by Texas family caregivers.

SESSION 2: Wisconsin Provider Needs Assessment

- Kim Whitmore, PhD, RN, CPN • College of Nursing, Marquette University, Milwaukee, WI

The Wisconsin Respite Survey was the first statewide survey to assess the current state of respite, current use, and barriers to receiving and providing respite in Wisconsin. Over 700 primary caregivers, respite providers, care recipients, and agencies completed this survey. Learn more about the survey, conducted as part of the WI Lifespan Respite Care grant, and the results.

Including Diverse Communities in Respite Opportunities – Lessons Learned from the Field

- Rosalyn Alber • Kinship and Lifespan Program Manager and Respite Program Director, Washington Aging and Long-Term Support Administration, WA
- Dana Allard Webb • Family Caregiver Support Program Manager and Lifespan Respite Grant Manager, Washington Aging and Long-Term Support Administration, WA
- Cheryl Miller, MLS • Director, Children and Family Services, Port Gamble S’Klallam Tribe, WA

The Lifespan Respite Washington Program strives to expand services to diverse populations. We are assisting Tribal populations to create relevant respite programs for their communities, developing materials for family caregivers of future WA Cares beneficiaries and are learning from Kingship Navigators how to better serve Kinship caregivers who are caring for a relative’s children. We will present strategies we are using to engage, educate and empower these family caregivers.
Scholar-Provided In-Home Novel Respite Training (SPRINT): Preparing Students to Care for Children with Medical Complexity

- Emily Jean Davidson, MD, MPH • Attending Physician, Boston Children’s Hospital, Jamaica Plain, MA
- Erin MacNeil, RN, MSN, NP-C • Marathon Nursing, Braintree, MA
- Sarah Wells MSN, RN, CPN, CWOCN • Nurse Practice Specialist, Boston Children’s Hospital, Boston, MA

Scholar Provided In-Home Novel Respite Training (SPRINT) is a respite innovation grant designed to meet the critical shortage of home nursing care and respite for children with medical complexity. An interdisciplinary team including parent, physician, and nurse will describe the SPRINT model, lead participants through a sample simulation on professionalism for respite providers, discuss preliminary findings and engage participants in an in-depth discussion of respite strategies for children with medical complexity and the use of student-provided in-home respite.

“A Gathering Place” – Building Community and Faith-Based Respite and Supports for Caregivers in the City of Buffalo

- Daysi Ball • Director, BFNC Hope Center Economic Impact Programs and Senior Support Services, Buffalo Federation of Neighborhood Centers, Buffalo, NY
- Kimberly Leonard • Assistant Long-Term Care Coordinator, Erie County Department of Senior Services, Buffalo, NY
- Aaron Carlson • Executive Director, Hearts and Hands: Faith in Action, Buffalo, NY

Learn about “A Gathering Place,” a collaboration in the City of Buffalo between Erie County Senior Services, community-based organizations and faith-based partners to provide access to respite programs and support services for caregivers predominantly in communities of color. “A Gathering Place” operates in local senior centers and churches adapting use of evidence-based curriculums to educate caregivers to promote their own self-care and positive behavior change for long term sustainability.

Respite ≠ Failure: Changing the Narrative of Respite

- Carolyn Harris • Respite Coordinator, Empower Simcoe, Barrie, Ontario, Canada
- Laurie Straughan • Supports and Services Manager, Empower Simcoe, Barrie, Ontario, Canada

Raising the bar starts with changing the narrative. This session will look at a person-centered approach where the caregiver of someone with an intellectual disability is identified as the person supported and services are created for them and with them. Learn how we implemented Respitality into our menu of respite services and changed the way we plan respite for all age groups. We will review: caregiver-driven programming; personal outcomes for caregivers; key messages; and transferring this narrative to other respite programs.
Musical Memories Café: Innovation, Impact, Replication, and Sustainability

Governor’s Ballroom E

- **Steven J. Harvey, PhD** • Chief Executive Officer, Guided Decisions, Buffalo, NY
- **Carolyn Panzica** • Executive Director, West Falls Center for the Arts, Musical Memories Café, West Falls, NY

Musical Memories Cafe (MMC) is an innovative program with demonstrated impact that serves caregivers, loved ones with dementia and Alzheimer’s, and isolated older adults through a culturally responsive, shared respite experience. We use evidence-based assessments to provide caregivers with targeted interventions by linking them to community resources. Finally, MMC has an innovative online self-directed training portal that trains organizations to implement MMC, sustain it, train volunteers, and join a community of other MMC organizations.

5:30 – 8:30 PM **EXCURSION: Dutch Apple Dinner Cruise**

(reservation required – there is a pre-paid fee associated with this event)
Thursday Morning, May 23, 2024

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

7:30 – 9:00 AM  Breakfast  

8:30 – 10:00 AM  MORNING PLENARY SESSION  

KEYNOTE PRESENTATION

Atalaya Sergi • Director,  
AmeriCorps Seniors, Washington, DC  

Meeting the National Strategy Goal of Growing  
the Respite Care Workforce through AmeriCorps Seniors

10:00 – 10:15 AM  Break

10:15 – 11:15 AM  BREAKOUT SESSION D

Piloting Virtual Reality at In-home and Drop-in Respite Programs  

State AB

• Kelly Allen • Partners In Caring Respite Program Manager, Lifespan of Greater Rochester, Inc., Rochester, NY

• Katy Allen • Division Leader Caregiver Services, Lifespan of Greater Rochester, Inc., Rochester, NY

• Cassidy Macdonald • Education Coordinator, Lifespan of Greater Rochester, Inc., Rochester, NY

Innovative digital technologies, specifically virtual reality (VR), are emerging as a solution to improve social support for community-dwelling persons living with memory loss and their care partners. This presentation describes a community-based participatory research project examining the implementation of VR into Lifespan of Greater Rochester’s Partners In Caring (PIC) respite program. Identified barriers and facilitators to implementing the VR intervention will be shared. Findings, tips and lessons learned will be discussed for successful VR implementation.
Raise the Bar for Supporting Family Caregivers through the Charting the LifeCourse Lens  
Jane St. John - Lead Product Development Specialist, LifeCourse Nexus, Kansas City, MO  
Barbara Sapharas - LifeCourse Nexus Coach, Family Resource Network of Ohio, Willoughby, OH

This session will “Raise the Bar for Respite” by sharing strategies and tools for supporting family caregivers. These include Charting the LifeCourse Respite Tools and the new Skill Building for Respite Series, including an interactive demonstration of a hands-on learning activity. When professionals receive the training and development to utilize these resources, they are better able to “Raise the Bar” in supporting family caregivers to take short breaks while still acknowledging and honoring their caregiving role.

Mobilizing Family Caregivers as Policy Advocates  
Siena Ruggeri - Community Engagement Consultant, Community Catalyst, Washington, DC

This session will share learnings from Community Catalyst’s past and current work mobilizing state coalitions of family caregiver leaders across the country. By equipping family caregivers with training and technical assistance, family caregivers grew their self-advocacy skills and connected their experiences of caregiving to a broader movement for policy change. The session will feature case studies and strategies for engaging with and mobilizing diverse coalitions of family caregiver leaders.

Care of the Invisible Patient: The Caregiver Support and Respite Connections Program  
Kathryn Sullivan, LMSW - Social Worker, Palliative Medicine and Supportive Care, Erie County Medical Center, Buffalo, NY  
Kimberly Leonard - Assistant Long-Term Care Coordinator, Erie County Department of Senior Services, Buffalo, NY

The Caregiver Support and Respite Connections Program is an innovative collaboration between an urban safety net hospital and the Erie County Department of Senior Services. This partnership creates a bridge of communication between the hospital and the Area Agency on Aging (AAA) and a continuum of compassion for family caregivers, who care for our aging, vulnerable, and sickest patients. By proactively assessing this often-overlooked need, we are working to reduce the cycle of morbidity while improving our patients’ outcomes.
SHARES ESSSION

SESSION 1: RAISE the Bar for Innovative Adventure-Based Memory Camps
- Rachel Watkins-Petersen • Project Manager, Respite Care Association of Wisconsin, Appleton, WI

Memory Camp is an innovative approach to respite and offers individuals with dementia and their families three nights and two full days of fun and relaxation at a beautiful camp in the north woods of Wisconsin. The session will describe planning for the camp sessions, campers’ experiences ages 5-95, recruitment and training of volunteers, campers’ responses, and how to replicate adventure-based camps, like Memory Camp, in your state.

SESSION 2: Dementia Friends New York Champion Information Session
- Dona Giannotti • Community Relations Manager, PSS, New York City, NY

Dementia Friends is a global movement that is changing the way people think, act, and talk about dementia. The goal of the Dementia Friends Session is to help community members understand dementia and the small things they can do to make a difference for people living with dementia. Join Dementia Friends New York as a Champion and help spread Dementia awareness one person at a time! A handbook will be provided to all participants.

From Volunteerism to the Respite Workforce:
An AmeriCorps Seniors Demonstration Program in New York
- Doris Green • Executive Director, New York State Caregiving and Respite Coalition, managed by Lifespan, Rochester, NY
- Sarah Tremblay • Portfolio Manager, Northeast Region, AmeriCorps
- Sharon Cackett • Assistant Director, New York State Caregiving and Respite Coalition, Clinton, NY

Six rural counties in NYS are part of an AmeriCorps Seniors demonstration program aimed at providing respite to caregivers. The project is designed to recruit, train and place 225 volunteers who are 55+. The goal is to then transition 40% of the volunteers into the paid workforce as respite providers through continuing education and job coaching. In this large geographic area, volunteer recruitment, training and respite service delivery methods are tailored to fit local needs.
SHARED SESSION

SESSION 1: College Students’ Experiences Providing In-Home Respite: Implications for Training and Support

- Ashley Woodman • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA
- Elodie Carel • Clinical Research Assistant, Center for Autism at Children’s National Hospital, Rockville, MD

The present study explored the perspectives of college students (n = 189) on their past experiences providing respite care to families of children/adults with intellectual and developmental disabilities. The goal of this study was to identify perceived challenges, successes, and training needs in order to design evidence-based initiatives to recruit and train college students as respite care providers. In this session, we will summarize our findings and lead an interactive discussion around curriculum development.

SESSION 2: Development of a Student Respite Toolkit

- Kim Whitmore, PhD, RN, CPN • College of Nursing, Marquette University, Milwaukee, WI

The Student Respite Toolkit is a free online resource that was developed to increase the number of students who provide respite care to family caregivers. The toolkit provides background on the importance of respite, an overview of existing model student respite programs, ways to connect students to existing respite programs, and step-by-step guidance on how to establish and maintain a student respite program. A Student Respite Collaborative was also established to connect academic partners and program staff involved in student respite programs to share ideas, best practices, and identify potential collaborative opportunities.

11:15 – 11:30 AM  Break
**11:30 AM – 12:30 PM**

**BREAKOUT SESSION E**

**Respite Care Among Parents of Autistic Children/Adults: Findings from a National Survey**  
*State AB*

- **Ashley Woodman** • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA
- **Tihitina Bekele** • Doctoral Student, Developmental Science, University of Massachusetts Amherst, Amherst, MA

In this session, we will summarize and discuss our findings from a national survey of 539 parents of autistic children and adults. This study aimed to understand to what extent parents of autistic children/adults use respite care services as well as their level of satisfaction with finding and keeping a quality provider. Among those who had never used respite care services, barriers to access were examined.

**Introducing the ARCH 2024 Innovative and Exemplary Respite Services**  
*Kelsey's*

- **Casandra Firman, MS** • ARCH Evaluation Consultant, ARCH National Respite Network and Resource Center, Port Townsend, WA
- **Susan Summers, PhD** • ARCH Evaluation Consultant, ARCH National Respite Network and Resource Center, Seattle, WA
- **Carolyn Panzica** • Executive Director, West Falls Center for the Arts, Musical Memories Café, West Falls, NY
- **Jacqueline Raxter** • Behavioral Health Program Manager, C.H.A.I. (Caregiving Helping Aid Initiative), Chaldean Community Foundation (CCF), Sterling Heights, MI
- **Jeanette O'Hara** • Founder, Will’s House, Tulsa, OK
- **Molly Brown** • Chief Executive Officer, Saint Louis Crisis Nursery, St. Louis, MO

During this session, Casandra Firman and Susan Summers with the ARCH National Respite Network and Resource Center will introduce model respite services recognized by ARCH as Innovative and Exemplary in 2024. 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.

**Adult Day Services – A National Respite Opportunity**  
*Capitol AB*

- **Doris Karpeh-Diaz** • Director, Centro de Amigos, Spanish-language Social Adult Day Center, Haverstraw, NY
- **William Zagorski** • Board Chair, National Adult Day Services Association, Nashville, TN

The continuum of Adult Day Services continues to expand and serve individuals of all ages and needs and their caregivers. Programs continue to innovate and serve specific and diverse populations as well as become more sophisticated in collecting data and showing the
quantitative value of the services provided, to the recipient, the caregiver, and the community at large. Join us for an exciting overview of the latest research, trends, and promising practices in Adult Day Services. The session will also explore working WITH and IN the Latino community with culturally and linguistically competent caregiving skills by featuring an adult day services program that provides services for Latino caregivers.

SHARED SESSION

**SESSION 1: Bottoms Up! Ground Floor Approaches for Local Patient and Caregiver Support**

- Phil Di Sorbo, MS, BCPA • Director, Senior Life Transitions Program, Saratoga Senior Center, Saratoga Springs, NY

Learn some of the core building blocks of a medical/social partnership to bring innovative care to the most vulnerable, using the strengths of your local community, including a source of volunteers that is waiting to be tapped. A thought leader in hospice and palliative care applies the guiding principles of a niche program to a much broader target of adults aged 50+ who have a serious illness - a fast growing demographic in our communities.

**SESSION 2: The Touch Program: Supporting Grieving Caregivers**

- Jack Read • Respite Voucher Program Manager, Tennessee Respite Coalition, Nashville, TN

When caregivers lose the person they care for, they experience a multitude of emotions: grief, loneliness, guilt, confusion, even relief. Respite care doesn’t end with the passing of a care recipient. The Touch Program provides a day of respite spa services for recently bereaved caregivers who don’t often receive the same amount of comfort they gave to their loved ones; this vital service is innovating how Tennessee supports caregivers once they have stopped being caregivers.

**Building Capacity Across the State to Increase Respite Access for All Caregivers**

- Aietah Stephens • Executive Director, Sooner SUCCESS, and Oklahoma Lifespan Respite Voucher Grant Program, Oklahoma City, OK

- Talena Ford • Programs Administrator, Lifespan Respite Voucher Program, Oklahoma Human Services, Oklahoma City, OK

Building capacity to increase respite access for all caregivers is the foundational approach in the partnership between Oklahoma Aging Services and Sooner SUCCESS under the Lifespan Respite Grant Voucher Program. Coordinated efforts across statewide respite voucher programs will be shared. Intentionality, cultural competency and strategic outreach to increase the number of underserved caregiver populations in Oklahoma is a priority. This successful model to improve care coordination translates to better outcomes and respite access for caregivers.
State Respite Care Policy and Innovations

- **FACILITATOR:** Ella Taggart • Senior Research Analyst, National Academy for State Health Policy (NASHP), Washington, DC
- **Kimberly Hodges** • Policy Associate, National Academy for State Health Policy (NASHP), Washington, DC
- **Lynn Gall** • Manager, Family Caregiver Support and Lifespan Respite Programs, Wisconsin Department of Health Services, Madison, WI
- **Deana Prest** • Caregiver Support Program Director, NYS Office for the Aging, Albany, NY

This session will feature state policies and innovations to improve access to respite care and to drive toward implementing the respite care actions within the National Strategy to Support Family Caregivers. A national speaker from NASHP will highlight emerging respite care innovations in Medicaid waivers. The session will also feature state policymakers from New York and Wisconsin who administer their Lifespan Respite grants and other caregiver supports, who will discuss innovative caregiver resources, outreach to employers, respite care vouchers, registries, and training curricula.

**SHARED SESSION**

**SESSION 1: Raise the Bar: Make Transportation Part of Your Respite Solution**

- **Jane Mahoney** • Training and Technical Assistance Specialist, National Aging and Disability Transportation Center - Easterseals, Menomonie, WI

Transportation is something that most caregivers provide for the people they are caring for, yet assistance with transportation is rarely part of the conversation when caregiver support plans are created. This session delves into how community transportation programs can be used as a form of respite and introduces tools to help incorporate transportation into caregiver support plans.

**SESSION 2: Expanding Your Toolkit with Volunteer Transportation**

- **Aaron Carlson** • Executive Director, Hearts and Hands: Faith in Action, Buffalo, NY

Volunteer transportation programs can save working caregivers from utilizing personal time off while ensuring their loved ones have access to reliable, safe, and socially engaging transportation. Learn how volunteer transportation is different from public transportation or rideshare programs. Explore the added benefits of volunteer transportation, such as waiting in a doctor’s office with your loved one to ensure they do not get lost or feel anxious, carrying and putting away groceries, and socialization.

12:30 – 12:45 PM  Break
Thursday Afternoon, May 23, 2024
12:45 – 2:45 PM  LUNCH and CLOSING PLENARY SESSION
Governor’s Ballroom

PANEL DISCUSSION

Multisector Plans for Aging to Advance Respite and Family Caregiver Support

FACILITATOR:
Carrie Graham, PhD
Director, Aging and Disability Policy
Center for Health Care Strategies (CHCS), Hamilton, NJ

PANELISTS:
Donna Benton
Assistant Dean of Diversity and Inclusion; Director of the USC Family Caregiver Support Center (FCSC); Associate Research Professor of Gerontology
USC Leonard Davis School of Gerontology, Los Angeles, CA

Andrew Lebwohl
Director, Center for the Master Plan for Aging
Office of Aging and Long Term Care
New York State Department of Health, Albany, NY

Mindy Ulstad
Chief of the Bureau of Senior Programs
Missouri Department of Health and Human Services, Jefferson City, MO

A Multisector Plan for Aging (MPA) (also known as Master Plan for Aging in some states) is a 10+ year blueprint that each state undertakes independently for restructuring state and local policies and for convening a wide range of cross-sector collaborators to address the needs of older-adult populations. At least half the states are developing or have completed an MPA. The goal is for states to create a coordinated system of high-quality care and support services that promote healthy aging, independent living, and social engagement.

MPAs can also serve as roadmaps for policies and programs that address the needs of family caregivers and align with the National Strategy to Support Family Caregivers. This panel of national and state leaders will highlight the significant ways several states are taking action on the National Strategy to Support Family Caregivers through Multisector Plans for Aging.

2:45 – 3:00 PM  WRAP-UP and CONFERENCE END

2025 National Lifespan Respite Conference Announcement
Speakers

Welcome

Alison Barkoff
Performing the duties of the ACL Administrator and Assistant Secretary for Aging
Administration for Community Living
U.S. Department of Health and Human Services

Alison Barkoff was sworn in as Principal Deputy Administrator on January 20, 2021, and is currently performing the duties of the ACL Administrator and the Assistant Secretary for Aging. She provides executive leadership and coordination for ACL programs nationwide and advises the Secretary of the Department of Health and Human Services (HHS) on issues affecting people with disabilities and older adults.

Under her leadership, ACL is working with partners across HHS and the federal government on initiatives and interagency approaches to issues that affect people with disabilities and older adults, such as expanding access to home and community-based services (HCBS) and affordable, accessible housing; strengthening the direct care workforce; increasing competitive, integrated employment for people with disabilities; and advancing equity, to name just a few.

Keynote

Jason Resendez
President and CEO
National Alliance for Caregiving

Jason Resendez is a nationally recognized healthcare strategist and advocate. He currently serves as the President and CEO of the National Alliance for Caregiving, where he leads research, policy, and programmatic initiatives to build health, wealth, and equity for America’s 53 million family caregivers. In 2023, Jason was named one of the most consequential leaders in health, science, and medicine by STAT News.

Jason has advised federal agencies and organizations working to advance equity for communities of color, including the National Institute on Aging, the National Academies of Medicine, the Administration for Community Living, and the Congressional Hispanic Caucus Institute (CHCI). He has also served as a volunteer policy advisor for the presidential campaign of President Joe Biden.

Earlier in his career, Jason worked at the nation’s leading Latino civil rights organizations UnidosUS and the education arm of the League of United Latin American Citizens (LULAC).

Prior to joining NAC, Jason was the founding executive director of the UsAgainstAlzheimer’s Center for Brain Health Equity where he pioneered the concept of Brain Health Equity through peer-reviewed research, public health partnerships, and public policy. In 2020, Jason was named one of America’s top influencers in aging by PBS’s Next Avenue alongside Michael J. Fox and Surgeon General Dr. Vivek Murthy. He has been quoted by The New York Times, The Washington Post, The Wall Street Journal, STAT News, Time, Newsweek, and Univision on issues related to caregiving and health equity. Jason is from South Texas and graduated from Georgetown University.
Greg Link, MA  
Director, Office of Supportive and Caregiver Services  
Administration for Community Living, Administration on Aging  
U.S. Department of Health and Human Services

Greg Link is the Director of the Office of Supportive and Caregiver Services with the Administration for Community Living/U.S. Administration on Aging, which oversees programs funded under the Older Americans Act (OAA), including Title III-B in-home supportive services, Title III-E National Family Caregiver Support Program as well as ACL’s Alzheimer’s disease programs. Most recently, Greg’s team, in collaboration with a range of stakeholders from across the public and private sectors developed and released the 2022 National Strategy to Support Family Caregivers. The Strategy is intended to serve as a roadmap for the nation for better recognizing and supporting family and kinship caregivers.

Greg and his team also provide general oversight and technical assistance to the aging network on a range of program areas, including the Lifespan Respite Care Program, Information and Referral, family caregiver support programs and policies, housing, employment, transportation, LGBT aging, and Holocaust Survivors.

Alexandra Drane  
Co-Founder and CEO  
ARCHANGELS

Alexandra Drane is co-founder and CEO of ARCHANGELS. She co-founded Eliza Corporation (acquired by HMS Holdings Corp: HMSY), Engage with Grace, and three other companies (all boot-strapped). A serial entrepreneur, she is also a cashier-on-leave for Walmart. She believes communities are the front line of health, that caregivers are our country’s greatest asset, and that we need to expand the definition of health to include life.

Alexandra sits on the RAND Social and Economic Policy Advisory Board, the Leadership Council for the Rosalynn Carter Institute, the Entrepreneurs Council for The United States of Care, and Harvard Medical School’s Executive Council of the Division of Sleep Medicine. She is a member of the Board of Directors of C-TAC and has served as a vice chair of the Trustee Advisory Board at Beth Israel Deaconess Medical Center from 2012-2020 and returned to the role in 2021. She also serves on the Board of Advisors for Open Notes. She served for 7 years as a Governor appointed member of the Executive Committee for the Board of Directors for MassTech, until March 2022. Alex was named to the first ever Care100 list in 2020, a Top Women in Healthcare’s Entrepreneur of the Year by PR News, one of Disruptive Women in Health Care’s Women to Watch, one of Boston Globe’s Top 100 Women Leaders, and listed in Boston Business Journal’s “40 Under 40”, as well as an inventor on multiple patents. She joined Prudential Financial as a Wellness Expert for a film series called “The State of US” that was turned into a national ad campaign and generated close to two billion impressions. She has one hobby outside of her passion for revolutionizing health care, and her love of family and adventure...car racing.
Atalaya Sergi
Director
AmeriCorps Seniors

Atalaya Sergi has 20 years of experience in service, community engagement, and education. She has worked in public school districts and the nonprofit sector, bringing private and public organizations together to ensure people of all ages, and those in underserved communities, thrive. Atalaya most recently served as the vice president of strategic partnerships and programming at Jumpstart for Young Children, Inc. There she managed AmeriCorps State and National and AmeriCorps Seniors programs as a federal grantee, launching her former organization’s only AmeriCorps Seniors Foster Grandparent program.

Atalaya has been a member of several advisory committees, councils, and coalitions, including as a co-founder of Los Angeles Generation to Generation, which focused on engaging older adults in volunteerism to support young children in Los Angeles County. She has been recognized as a PBS Next Avenue Influencer in Aging and was selected as an Encore Public Voices Fellow, using her time to write about the positive impact seniors can have in educational settings.

Atalaya earned a master’s degree in social work from Virginia Commonwealth University and a bachelor’s degree in sociology from the University of Virginia.

Panel Discussion

Multisector Plans for Aging to Advance Respite and Family Caregiver Support

FACILITATOR

Carrie Graham, PhD
Director, Aging and Disability Policy Center for Health Care Strategies (CHCS)

Carrie Graham, PhD, is the director of Aging and Disability Policy at the CHCS. Dr. Graham oversees CHCS’ portfolio of work to improve care delivery for older adults and people with disabilities; with a special focus on those who need long-term services and supports (LTSS) and those dually eligible for Medicare and Medicaid. She provides direct technical assistance to 20 states that are developing Multisector Plans for Aging.

Dr. Graham has been working in the field of aging research, health policy, and evaluation research for more than 25 years, including working as a health policy evaluator in her role as professor at the University of California, San Francisco (UCSF) Institute for Health and Aging; and at the UC Berkeley School of Public Health. She also worked on Medicare legislation in 2018 as a Fellow in the U.S. House of Representatives, Committee on Ways and Means, Health Subcommittee. In 2019 she acted as consultant to Governor Newsom’s Master Plan for Aging.

Dr. Graham holds a doctorate in medical sociology from UCSF and a master’s degree in gerontological studies from the Scripps Gerontology Center at Miami University. She obtained her bachelor’s degree from University of California, San Diego in sociology and African studies.
PANELISTS

Donna Benton, PhD
Assistant Dean of Diversity and Inclusion
Director of the USC Family Caregiver Support Center (FCSC)
USC Leonard Davis School of Gerontology

Donna Benton, PhD, is a research associate professor of gerontology and director of the Family Caregiver Support Center at the USC Leonard Davis School of Gerontology. Dr. Benton played a key role in development and implementation of California’s Master Plan for Aging, and served on the Equity in Aging Advisory Committee for the Master Plan. She is a member of the CA Coalition on Family Caregiving, Work Family coalition and the Elder Justice Coalition and continues to work on the CA Master Plan of Aging.

She has worked in the field of aging for more than 30 years. Her volunteer experience with the Gray Panthers in high school inspired her career as an advocate for improving how we all view the natural process of aging. She is committed to promoting collaborative partnerships that enhance service delivery for families caring for older adults with long-term memory and health problems.

Andrew Lebwohl
Director, Center for the Master Plan for Aging
Office of Aging and Long Term Care
New York State Department of Health

Andrew Lebwohl serves as the Director for the Center for the Master Plan for Aging in the New York State Department of Health. Prior to his current position, Andy worked as the Director of the Center for Aging and Long Term Care Finances and Supports. Before coming to the Department of Health, Andy worked in affordable housing financing at the Division of Homes and Community Renewal. Andy’s work has focused extensively on social determinants of health and the need for comprehensive systems to support wellness and aging. Before entering public service, Andy developed expertise as an attorney and financial advisor to distressed companies.

Mindy Ulstad
Chief of the Bureau of Senior Programs
Missouri Department of Health and Human Services

Mindy Ulstad has more than ten years of experience working with older adult populations, and almost 30 years of experience working with vulnerable populations. The Bureau of Senior Programs oversees the Older Americans Act funding for the state and works closely with the ten Area Agencies on Aging to develop programs and services to help older Missourians remain safe, healthy, and independent in their environment of choice. The Bureau also oversees the Senior Community Service Employment Program, the MIPPA Program (Medicaid Improvements for Patients and Providers Act), and state-funded programs that help older Missourians age with dignity. These programs include Naturalization for Older Legal Immigrants and Refugees, five Senior Independent Living Programs across the state, the Customized Caregiver Training and Relief Program, the Alzheimer’s State Plan Taskforce, the Give 5 Program (a volunteer program), and the state’s Century Club.

Mindy is also the State of Missouri lead for the Master Plan on Aging, Missourians Aging with Dignity. She strives to collaborate with stakeholders and constituents across the state to ensure that services meet the current needs of older Missourians and help plan for their future needs.
Conference Planning Committees

National Conference Planning Committee
Tracy Cieniewicz  •  Alabama Lifespan Respite, AL
Megan Bettinger  •  Colorado Respite Coalition, Easterseals Colorado, CO
Talena Ford  •  Oklahoma Lifespan Respite Program, Oklahoma Human Services, OK
Cory Lutz  •  Helping Hands of Vegas Valley and Nevada Respite Care Coalition, NV
Jack Read  •  Tennessee Respite Coalition, TN
Lisa Schneider  •  Respite Care Association of Wisconsin, WI
Kathy Mayfield Smith  •  South Carolina Respite Coalition, SC
Marilyn Sword  •  Idaho Caregiver Alliance, ID
Kim Whitmore  •  Marquette University College of Nursing, WI

State Conference Planning Committee
Doris Green  •  NYSCRC
Sharon Cackett  •  NYSCRC
Abbey Derepentigny  •  NYSOFA
Deana Prest  •  NYSOFA

Unlock Better CAREGIVER SUPPORT with TCARE
We are an ACL Evidence-Based Program that identifies caregivers on the verge of burnout and guides them toward personalized interventions.

Transform Your Support Programs:
Discover how TCARE can make a difference!
Contact Linda Miller  •  918-991-8581  •  linda@tcare.ai

SUPPORTING FAMILY CAREGIVERS IS Age-Friendly Care

RAISE the Bar for Respite
Strategies to strengthen family caregivers
Conference Exhibitors

AARP New York
states.aarp.org/new-york

Albany Guardian Society
albanyguardiansociety.org

Alzheimer's Association,
New York State Coalition
alz.org/centralnewyork/about_us/new-york-state-coalition

AmeriCorps Seniors Demonstration Program – NYSCRC/Lifespan
nyscrc.org/americorps

CARF International
carf.org

Community Health Access to Addiction and Mental Health Care Project (CHAMP)
oasas.ny.gov/champ-community-health-access-addiction-and-mental-health-care-project-0

Grandfamilies & Kinship Support Network
gksnetwork.org

Mohawk Valley Physicians Health Care (MVP)
mvphealthcare.com

National Academy for State Health Policy
nashp.org

National Adult Day Services Association
nadsa.org

New York Relay Service
nyrelay.com

New York State Adult Day Services Association
nysadsa.memberclicks.net

New York State Caregiving and Respite Coalition
nyscrc.org

New York State Office for the Aging, NY Connects
nyconnects.ny.gov

NYSARC Trust Services
nysarctrustservices.org

Parkinson’s Foundation
New York New Jersey Chapter
parkinson.org/nynj

Rendever
rendeever.com

Respitrack
respitrack.com

Upstate New York Poison Center
(Upstate Medical Center)
upstate.edu/poison

Westfalls Center for the Arts/
Musical Memories Café
westfallsartcenter.org/memory-cafe167513f0
Schedule At-a-Glance

Monday, May 20, 2024
6:00 – 8:00 PM ⊗ Early Conference Registration
7:00 – 8:00 PM ⊗ Lifespan Respite Grantee and Partner Networking Reception (by invitation only)

Tuesday, May 21
8:00 – 9:00 AM ⊗ Registration and Breakfast for Lifespan Respite Grantee and Partner Learning Symposium Attendees
9:00 AM – 4:00 PM ⊗ Lifespan Respite Grantee and Partner Learning Symposium (by invitation only)
3:00 – 8:00 PM ⊗ National Conference Registration
6:00 – 9:00 PM ⊗ OPENING SESSION
National Respite Conference Welcome Dinner
KEYNOTE: Jason Resendez, President and CEO, National Alliance for Caregiving
Meeting the Diverse Needs of Family Caregivers in Implementing the National Strategy to Support Family Caregivers
RECOGNITION: ARCH 2024 Innovative and Exemplary Respite Services

Wednesday, May 22
7:30 AM – 5:00 PM ⊗ Registration and Exhibits
7:30 – 9:00 AM ⊗ Breakfast
9:00 – 10:30 AM ⊗ MORNING PLENARY SESSION
WELCOME (Video): Alison Barkoff, Performing the duties of the ACL Administrator and Assistant Secretary for Aging, Administration for Community Living, U.S. Department of Health and Human Services
KEYNOTE: Greg Link, Director, Office of Supportive and Caregiver Services, Administration for Community Living, Administration on Aging, U.S. Department of Health and Human Services
Raising the Respite Bar: The National Strategy to Support Family Caregivers as a Leadership Framework
10:30 – 11:00 AM ⊗ Break
11:00 AM – 12:00 PM ⊗ BREAKOUT SESSION A
12:00 – 12:15 PM ⊗ Break
12:15 – 2:00 PM ⊗ LUNCHEON PLENARY SESSION
KEYNOTE: Alexandra Drane, Co-Founder and CEO, ARCHANGELS
Any Care Counts to Your Top, Bottom, and Heart-Line
2:00 – 2:15 PM ⊗ Break
2:15 – 3:15 PM ⊗ BREAKOUT SESSION B
3:15 – 3:45 PM ⊗ Break
3:45 – 4:45 PM ⊗ BREAKOUT SESSION C
Evening ⊗ DINNER CRUISE

Thursday, May 23
7:30 AM – 3:00 PM ⊗ Registration and Exhibits
7:30 – 9:00 AM ⊗ Breakfast
8:30 – 10:00 AM ⊗ MORNING PLENARY SESSION
KEYNOTE: Atalaya Sergi, Director, AmeriCorps Seniors
Meeting the National Strategy Goal of Growing the Respite Care Workforce through AmeriCorps Seniors
10:00 – 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 – 12:45 PM ⊗ Break
12:45 – 2:45 PM ⊗ LUNCHEON PLENARY SESSION
CLOSING PANEL: (to begin about 1:15 pm)
Multisector Plans for Aging to Advance Respite and Family Caregiver Support
FACILITATOR: Carrie Graham, PhD, Director of the Aging and Disability Policy, Center for Health Care Strategies (CHCS)
PANELISTS:
Donna Benton, PhD, Assistant Dean of Diversity and Inclusion, Director of the USC Family Caregiver Support Center (FCSC), USC Leonard Davis School of Gerontology
Andrew Lebwohl, Director, Center for the Master Plan for Aging, Office of Aging and Long Term Care, New York State Department of Health
Mindy Ulstad, Chief of the Bureau of Senior Programs, Missouri Department of Health and Human Services
2:45 – 3:00 PM ⊗ WRAP UP and CONFERENCE END
2025 National Lifespan Respite Conference Announcement