

2017 NATIONAL LIFESPAN RESPITE CONFERENCE OCTOBER 11-13 | HUNTSVILLE, ALABAMA

Preliminary Conference Program

Tuesday Evening, October 10, 2017

4:00 pm – 6:00 pm Early Registration/Information Table

5:30 pm – 7:00 pm Reception for Lifespan Respite Grantees and Partners, Embassy

Suites Huntsville Back Patio (by invitation only)

Wednesday, October 11, 2017

8:00 am – 5:00 pm Registration/Information Table

8:30 am - 4:00 pm Lifespan Respite Grantee and Partner Learning Symposium

(by invitation only)

Wednesday Evening, October 11, 2017

5:30 – 10:00 pm Welcome Reception

The reception will begin in the ballroom of the Embassy Suites with beverages, networking, and opening remarks at 5:00 pm. Buses will depart for Campus No. 805 from the Embassy Suites lobby at 6:15 PM.

Thursday Morning, October 12, 2017

7:30 - 5:00 pm

Registration/Information Table

For conference attendees staying at the Embassy Suites, the hotel provides a complete breakfast. For others, a limited continental breakfast will be available from 7:30 to 9:00 am.

Opening and Welcome

9:00 – 9:30 am Welcome Messages

Jill Kagan, ARCH National Respite Network and Resource Center

National Champions for Respite

Video Presentations from Congressional Champions of the Lifespan Respite Care Reauthorization Act (HR 2535; S 1188)



The Honorable Susan Collins (R-ME) U.S. Senate Washington, D.C.



The Honorable Jim Langevin (D-RI) U.S. House of Representatives Washington, DC

Cheryl Smith, Alabama Lifespan Respite Network and United Cerebral Palsy of Huntsville and the Tennessee Valley, Huntsville, AL

Additional Speaker TBA

9:30 - 10:30 am



Keynote Presentation

Al Condeluci, PhD CEO of Community Living and Support Services (CLASS), Pittsburgh, PA

For the past 44 years, AI has been associated with CLASS, a full service nonprofit organization supporting people with disabilities, where he currently serves as Chief Executive Officer. AI holds faculty appointments with the University of Pittsburgh's School of Health and Rehabilitation Sciences and School of Social Work. He serves as a consultant and collaborator, lectures extensively around the country and is the author of numerous books.

Al will share his own personal experience with caregiving and how it has shaped his current thinking. He will discuss the power of social capital to support caregivers, new research on community engagement patterns of families who have children with disabilities, and crafting meaningful respite options for children and adults with disabilities and older adults.

10:30-11:00 Break

11:00–12:15 PM Breakout Session A

A-1 Shared Session

Accessing Reeve Foundation Respite Care Grants

Angela Cantillon, Director, Paralysis Resource Center Operations Christopher & Dana Reeve Foundation, Short Hills, NJ

The Christopher & Dana Reeve Foundation provides a host of free programs and services to benefit those living with paralysis and the organizations that serve them. This presentation will provide an outline of all of our services and grants programs as well as highlight a new grant program that specifically serves organizations that provide respite care services to families living with a mobility limiting condition.

AND

Launch Your Own Caregiver College

Della Sanchez, LGSW, Alabama Cares Coordinator, South Alabama Regional Planning Commission Area Agency on Aging, Mobile, AL

To address the needs of adult family caregivers, staff of the South Alabama Regional Planning Commission/ Area Agency on Aging designed a "Caregiver College." The presenter will explain the components establishing a caregiver college, as well as the challenges encountered and lessons learned, and share success stories from caregivers who attended.

A-2 Lessons Learned in the Delivery of Respite Care for Military Families with Children Having Special Needs

Bonnie Storm, M.S. Ed, Senior Director, Respite Care, Child Care Aware of America, Arlington, VA

Child Care Aware® of America has been facilitating and improving on implementation of military Exceptional Family Member Program (EFMP) Respite Care for eight years. The program has evolved from initial concepts to full development by understanding families' needs and adapting the program to meet those needs. There are lessons learned and best practices for respite care implementation. The presentation is aimed at exploring best practices that might be considered by other respite care practitioners.

A-3 Valuing Lives - Wolf Wolfensberger and the Principle of Normalization

Al Condeluci, PhD, CEO of Community Living and Support Services (CLASS), Pittsburgh, PA

A film documenting the paradigm shift triggered by Wolf Wolfensberger's 1970's Principle of Normalization from institutions to community inclusion for people with disabilities will be shown during this session. Wolfensberger's efforts to teach a new generation of parents and professionals fueled a movement of positive change that continues today as new threats of institutionalization arise. The film calls forth today's leadership to combat devaluation and to promote inclusion and valued social roles for people with disabilities. After the film, what this means for respite and community supports will be discussed.

A-4 Put a Man on the Moon (and Know How Much It Costs): Identifying Costs and Benefits of Respite Care

Casandra Firman, Senior Staff, ARCH National Respite Network and Resource Center, Port Orchard, WA

MaryJo Alimena Caruso, M.Ed., T/TA Coordinator, FRIENDS National Resource Center for the Community-Based Child Abuse and Neglect Prevention Program (CBCAP), Sewickly, PA

We want to send a man into outer space. But, do we know how much it costs or if the price is truly worth it? The same questions may be asked about respite. Respite programs may be a sound investment in the health and well-being of individuals with special needs, families, and the larger community. What's less clear is its actual economic impact. This presentation highlights FRIENDS CBCAP resources to engage in true cost analysis!

A-5 Shared Session

Journey to Improved Respite: Mini-Grant and REST Outcomes in New York

Doris Green, MPA, Director, NYS Caregiving and Respite Coalition, Rochester, NY

The NYS Caregiving and Respite Coalition will provide information on the use of Mini Grants and the REST (Respite Education and Support Tools) model to implement or expand a variety of volunteer-based respite models in the state. The presentation will include discussion of the challenges and rewards of this initiative and evaluation and outcome data.

AND

It's Not as Easy as It Sounds: Lessons Learned from Caregiver-Directed Respite Voucher Programs

Alicia E. Blater, M.S., APR, Family Caregiver Support Program Consultant, Lifespan Respite Project Director, NC Division of Aging and Adult Services, Raleigh, NC

Susan E. Reed, Lifespan Respite Project Specialist, NC Division of Aging and Adult Services, Raleigh, NC

Why does a caregiver not use a respite voucher they've been awarded? How do we overcome these barriers to use? Participants will learn about North Carolina's experience with caregiver-directed respite vouchers through two statewide programs and what we learned from an evaluation of their case management experience and voucher award use. The specific evaluation was conducted with caregivers of a person with dementia, but many of the findings can apply to other caregiving populations.

A-6 Technology for the 21st Century Caregiver: Applications and Advances to Streamline Care Needs

Brandi Mason, M.Ed, Community Relations Director, Home Instead Senior Care, Huntsville, AL

Until now, technology has only played a modest role in supporting caregivers, but with today's technological advances it can play a more meaningful role. These advances include devices, applications, web sites, and services designed to streamline and simplify the caregiving experience. The presentation discusses online resources, wearable technology for monitoring, and ways for caregivers to stay a connected part of their loved ones' care.

Thursday Afternoon, October 12, 2017

12:15–2:00 Luncheon Keynote



"Witty, songwriter-storyteller with a flair for the creative, the dramatic, and the humorous."

"It is precisely her take on the ordinary that makes her work so extraordinary."

Village Voice

Christine Lavin Singer/Songwriter/Guitarist/Recording Artist, New York City, NY

Christine Lavin is a singer, songwriter, guitarist, and recording artist who has been based in New York City since 1976. She is currently working on her 23rd solo album. Christine performs concerts all over the US, Canada, and points beyond (Australia, Germany, and Israel). She is as well-known for her humor as she is for her extraordinary singing and song-writing abilities. She recently moved back to New York after taking care of her mother who is 97. She will share her personal caregiving experiences and how it affected her, and perhaps even sing a new song about it. Well aware of what it takes to be a caregiver, she recently extended an invitation for all caregivers to come to one of her shows. "So many caregivers work themselves to the bone and don't make time to have fun themselves."

2:00 - 2:15 Break

2:15-3:30 Breakout Session B

B-1 Developing a Legislative Agenda for a Respite Program Capacity Building Initiative

Dorinda A. Adams, Programs Manager, Office of Adult Services, State of Maryland Department of Human Resources, Baltimore, MD

Christine Schoenberger, MHS, Manager, Business Operations, Maryland Center for Developmental Disabilities, Kennedy Krieger Institute, Baltimore, MD

Maryland has funded Respite Care across the Lifespan via State funding since 1984. Developing a relationship with the state's General Assembly, a Governor Appointed Caregiver Council has provided strategies that have built a Respite Care Program Enhancement Plan via a statewide survey. This session will explore how using existing research partnerships and identifying key members of the legislature will work towards systemic changes that support all Family Caregivers with additional Respite Care in the state.

B-2 Developing and Using a Caregiver Simulation to Create Empathy Among the Non-Caregiving Community

Julie Smith, CSA, Home Instead Senior Care, Huntsville, AL

Creating and implementing a Caregiver Simulation can bring empathy and awareness to your community. Understanding the challenges facing family caregivers may help garner more support for those struggling to complete simple daily tasks. This session will walk participants through the steps in developing a successful Caregiver Simulation.

B-3 Alabama Head Injury Foundation: Caring for Traumatic Brain Injury

Dianne Pierson, M.Ed., Resource Coordinator, Alabama Head Injury Foundation, Huntsville, AL

Presenters will discuss the etiology of traumatic brain injury both in the civilian population as well as TBI associated with military service. Changes immediately after a TBI and lasting effects will be reviewed. How these changes can impact a survivor as well as respite providers and family members who may now be caregivers will be explored. Instruction/tips for how to address longer lasting effects/deficits will be provided along with examples to better communicate, adapt environment, and modify behaviors.

B-4 Redefining Respite

Wendy C Smith, Respite & Life Planning Coordinator, Home of Guiding Hands, El Cajon, CA

A broader and more responsive definition of respite can enhance quality of life in many ways for both clients and caregivers. A different perspective can redefine how respite benefits not just caregivers, but clients and all family members. New activities, choices and learning opportunities create a positive environment that focuses on client interests and success. Tear down walls of tradition and reconsider just what respite CAN be for the clients and families we support.

B-5 Lessons Learned: Methods and Outcomes from a 3-year Statewide Evaluation of Lifespan Respite in Nebraska

Jolene Johnson, Ed.D., Assistant Professor, University of Nebraska Medical Center, Omaha, NE

Sharon Johnson, NE Department of Health and Human Services (DHHS) Program Coordinator, DHHS Children & Family Services, Lifespan Respite Subsidy Program, Lincoln, NE

Family Caregiver outcomes will be the primary focus of a presentation on the statewide Lifespan Respite Evaluation completed in Nebraska. Three years of data provide a rich context for understanding the impact of respite services for family caregivers. The presentation will also include the methods, evaluation tools and information about the data dashboard.

B-6 | Enable Savings Plan: A National ABLE Program

Amelis Long, Enable Outreach Specialist, Enable Savings Plan, Omaha, NE

The Enable Savings Plan for people with disabilities is an opportunity to reach your potential by saving for your today and tomorrow. There are two major benefits: 1) Money in an Enable account does not impact eligibility for resource-based benefits, like SSI and Medicaid; and 2) Earnings are tax-free at the federal and state level. It's an ABLE account that lets you invest money in your name for qualified disability expenses including respite for your caregiver. Session will review eligibility, qualified expenses, impact to benefits and program features.

3:30-3:45 Break

3:45-5:00 Breakout Session C

C-1 Management of ALS and Parkinson's: Guidelines for Caregivers

Sherry Kolodziejczak, MS, OTR/L, Director of Therapy Services/ALS Care Clinic/Cardiac Rehab, Crestwood Medical Center, Huntsville, AL

It is important to recognize symptoms, caregiver support and treatment options for those living with Parkinson's Disease and Amyotrophic Lateral Sclerosis (ALS.) This presentation will cover an overview of both Parkinson's Disease and ALS including diagnosis and symptoms. Furthermore, the presentation will discuss the effects on self-care and mobility and current treatment options including respite and resources for caregivers.

C-2 The Respite Ministry: Building a Volunteer Respite Ministry for Dementia Care

Daphne Johnston, Director, The Respite Ministry, A Volunteer Based Dementia Community, Montgomery, AL

The Respite Ministry is a social model of dementia care that can be easily replicated in a faith-based community. The sense of purpose and belonging that one can achieve through joining a "volunteer" Respite program is beyond what the caregiver can accomplish alone at home. Respite trained volunteers and participants work together to identify "activity roles" for the participants that support success and feelings of contribution. A volunteer program is cost-effective, provides respite to both caregiver and participant, and helps provide meaning and hope for the person living with dementia.

C-3 The Role Family Camps Can Play in Providing Respite

Betsy Hopson, MSHA, Children's of Alabama, University of Alabama at Birmingham, Lincoln, AL

Ruth Brewbaker- BFA in Art; M.Ed, Rooftop Friends, Montgomery, AL

This presentation will explore the role that non-medical models, such as family camps, can play in achieving maximum independence and quality of life while providing much needed respite for families with special health care needs.

C-4 Securing Respite Programs through State Advocacy and Research

Rachelle Cummins, M.A., Research Director, AARP, Washington, D.C.

Jon Bartholomew, M.P.A., Government Relations Director, AARP, Oregon

Using data from the 2015 Caregiving in the U.S. study and 17 studies conducted by AARP in 2015, the analysis explores the relationship between caregiver respite care use and reported health status, stress, and length of time providing care. Taken separately, these public opinion polls have provided state legislators with insights about the importance of respite care services for family caregivers. AARP legislative advocacy efforts and policy implications will also be discussed in this session.

C-5 It's Not Rocket Science: Using Cable Television for Caregiver Outreach, Education, and Sharing Respite

Emily Kearns, PhD, MA, BA, MBA, Evaluator/Consultant, Massachusetts Lifespan Respite Coalition, Andover, MA

Stacey Hammerlind, MHA, Project Coordinator, Massachusetts Lifespan Respite Coalition, Belmont, MA

Amy Nazaire, MA, ABD, Director, Massachusetts Lifespan Respite Coalition, Hathorne, MA

It's Not Rocket Science offers a case study and replicable model for using local cable television to reach isolated caregivers; respite and other providers; and diverse community stakeholders. Massachusetts Lifespan Respite Coalition staff share the nuts and bolts of creating a show to reach caregivers with respite and support resources. This interactive session explores using cable television as a natural outreach, marketing, and educational infrastructure - a must for any respite coalition and respite movement!

C-6 "Me Time" - A Social and Recreational Program for Parents of a Child with Autism

Lucina Clarke, M.Ed., Executive Director, My Time Inc., Brooklyn, NY;

Esther Wilson, President, Your Needs Resource Center, Rosedale, NY,

Denise Jordan, Parent, My Time Inc, Brooklyn, NY

In learning more about "Me Time," a social and recreation program for parents of a child with Autism, parents will know the importance of taking time for oneself to relax, find solitude, rejuvenate and enjoy spending time alone and with others. They can give themselves permission to explore activities, accept themselves, and know that they are deserving of a break. Parents will realize that they can redefine who they are as a person and appreciate taking that break.

Thursday Evening, October 12, 2017

Dinner on Your Own in Huntsville - Rocket City USA!

Friday, October 13, 2017

7:30 am - 3:00 pm

Registration and Information Desk

For those staying at the Embassy Suites, the hotel provides a complete breakfast. For others, a limited continental breakfast will be available from 7:30 to 8:30 am.

8:30–9:15 am Morning Plenary: Keynote Speaker



The Honorable Lance Robertson

Assistant Secretary for Aging Administrator, Administration for Community Living U.S. Department of Health and Human Services Washington, D.C.

9:15 - 9:30 Break

9:30 - 10:45 Breakout Session D

D-1 Shared Session

Twitter Revolution: How *WE* Conquered the *Twitterverse* and Won Over Legislators

Joy Scott, Executive Director, Tri County Caregiver Relief, Yuba City, CA

This session provides an opportunity to learn how to use Twitter more effectively in the advocacy arena. Twitter is an information social network made up of 140-character messages called *Tweets*. Learn how to tweet and use it to advance your business or program, inform yourself about local news, affect policy change or simply share your feelings. There's one universal thing you need to know about Twitter: *JUST USE IT!*

AND

Developing a Policy Agenda for Respite Care

Spencer Blalock, DHA, LCSW, BCD, Co-chair, Mississippi Family Caregiver Coalition, Decatur, MS

This presentation will describe the challenges to creating a respite network with no previous state respite policy agenda in place. Participants will learn about policy agendas, how they are reached based on theory and history, and how they can positively affect society. Participants will also discuss methods for achieving consensus to create a respite policy agenda with policy informants and policy makers. The formation of the Mississippi Family Caregiver Coalition and the role of the State Task Force on Caregiving in developing and promoting respite and caregiver recommendations for the lifespan will be used as examples.

D-2 Crisis Nurseries: Using Respite Support to Alleviate Family Crisis and Improve Parent and Child Wellbeing

Amy Kendal-Lynch, Program Director, Maryville Crisis Nursery, Chicago, IL

Tiffanny Powell, Program Manager of Family Support Services, Children's Home + Aid, Bloomington, IL

Crisis Nurseries provide services 24 hours a day, 7 days a week to strengthen families by building protective factors for long term family stability. Through respite care services, crisis nurseries have become a critical community support for families experiencing crisis. The Crisis Nursery continuum of services begins with crisis child care and extends to referrals and linkages, parenting education, parent support groups, and home visiting services. We provide a trauma-informed approach using the ACES assessment.

D-3 A Musical Voyage

Mandy Hansen, Volunteer Coordinator, Tennessee Respite Coalition, Nashville, TN

Jennifer Abernathy, MSW, Executive Director, Tennessee Respite Coalition, Nashville, TN

Learn how the Music and Memory concept can be used in respite provision and how it helps caregivers and care recipients. In January 2017, the Tennessee Respite Coalition began the process to integrate Music and Memory with the Senior Companions Respite Program. The partnership is one of the first uses of the Music and Memory model to enhance the in-home respite experience.

D-4 Shared Session

Short Breaks, Big Impact: REST Delivers Education and Support to those who Provide Respite

Lois Sheaffer, Director, REST, Bloomingdale, IL

Wendy Berk, Program Analyst, REST, Bloomingdale, IL

REST is an evidence supported training program that uses a train-the-trainer approach to prepare individuals to provide respite. During this session, updated research data will be shared from the one-day workshops, showing that participants experience significant increases in their skills, knowledge, and confidence related to providing respite. The presenters also will explore how different states have adopted REST as a respite training model, and how family caregivers feel about respite they receive from trained REST Companions.

AND

REST Training Program - Prepare to Provide Care through Alabama Cares

Leisa Askew, Lee Russell Council of Governments, Area Agency on Aging, Alabama Cares, Opelika, AL

Mary Wedgeworth, South Central Alabama Development Commission, Area Agency on Aging, Alabama Cares, Montgomery, AL

REST (Respite, Education & Support Tools) provides the skills needed to provide quality respite assistance. Area Agencies on Aging in Alabama Cares are using REST to help create a network of individuals who are trained in providing quality, compassionate, and confident respite care to family caregivers. This session will be interactive and designed to prepare individuals to care for people across the lifespan who have chronic health care needs or disabilities.

D-5 Charting the LifeCourse: Respite/Short Breaks for Caregivers

Jane St. John, Community Inclusion and Field Research Specialist, National Community of Practice for Supporting Families, University of Missouri-Kansas City, Institute for Human Development, Kansas City, MO

Utilizing the newly-released *Charting the LifeCourse* Respite Booklet designed as a collaborative project between the National Community of Practice for Supporting Families and the ARCH National Respite Network and Resource Center, this interactive, hands-on workshop will help caregivers, and those who support them, to understand the meaning and importance of respite/short breaks. Presenters will also discuss how the *LifeCourse* Respite Tools can help family caregivers identify the possibilities and options that exist for respite, within and outside the formal paid service system, and begin to create a successful plan that uses these short breaks to enhance the lives of all family members.

D-6 Understanding Male Caregivers

Julie Smith, CSA, Home Instead Senior Care, Huntsville, AL

The caregiver world is changing as more men are faced with the responsibility of caring for a spouse, parent or child. Faced with a different set of challenges, men often approach caregiving with a new set of eyes. Understanding the male caregiver and how to help them avoid stress and burnout is key to helping them have a positive caregiving experience.

10:45 - 11:00 Break

11:00 - 12:15 Breakout Session E

E-1 Lift Off with Memory Cafes and Autism Eats: Exploring Innovative Café Respite Models

Emily Kearns, PhD, MA, BA, MBA, Evaluator/Consultant, Massachusetts Lifespan Respite Coalition, Andover, MA

A. Michael Bloom, MA, MS, BS, Director of Strategy & Innovation, LifeLinks, Inc., Chelmsford MA.

Lenard Zohn, Co-Founder and Autism Dad, Autism Eats, Andover, MA

This session introduces two innovative and replicable café respite models that add a new dimension to the concept of respite – light respite where care partners share food, stimulating activity, and a meaningful sense of inclusion and community. Massachusetts Lifespan Respite Coalition's mini grantees share their programs

and facilitate the opportunity to consider how you can start a café respite program in your community.

E-2 Creating Sustainable Volunteer-based Respite by Catalyzing Your Community

Lisa McCoon, Pause Program Director, Butler County Family and Children First Council, Hamilton, OH

Using a volunteer-based respite model, learn how to bring families needing respite out of isolation while catalyzing the local community to step in to fill the gap. From first conversations with early adopters through respite event logistics, such as safety, recruitment and retention of volunteers/community partners, family registration, event activities and program satisfaction, you will learn the necessary pieces needed to not only create respite opportunities, but also support families beyond the respite event.

E-3 Launch a Day Program for Those with Alzheimer's or Other Dementias so Family Caregivers Can Take Off

Janet B. Altman, Executive Director, South Carolina Respite Coalition, Columbia, SC

South Carolina has a variety of day programs, staffed primarily by trained volunteers, which serve individuals in the early and middle stages of dementia. These programs enable family caregivers to "take off" while their loved ones are launched into a "day with friends." Day programs for those with memory loss, disorientation, and impaired decision-making are in great demand. The presenter will survey 3 specialized programs which enable participants and family caregivers to take off with respite.

E-4 Don't Let Your Data Become Hidden Figures! Plan & Conduct Evaluation to Tell Your Respite Story

MaryJo Alimena Caruso, M.Ed., T/TA Coordinator, FRIENDS National Resource Center for the Community-Based Child Abuse Prevention Program, Sewickley, PA

Evaluation is a necessary part of program accountability. Identifying what to measure, having the right measurement tools and collecting the data doesn't have to feel like sending a spaceship to Mars! Knowing how to use those "hidden figures" to concisely communicate your respite program's impact on the participants and community is a part of telling your program's success story. Learn the process of engaging in meaningful evaluation to promote quality and demonstrate effectiveness!

E-5 Launching Respite Innovations Through a Lifespan Respite Program

Sarah Swanson, Family Support Outreach Coordinator, University of Nebraska Medical Center/Munroe-Meyer Institute, Omaha, NE

Ellen Bennett, MS, Respite Associate, University of Nebraska Medical Center/Munroe-Meyer Institute, Omaha, NE

Sharon Johnson, Lifespan Respite Network Coordinator, NE Department of Health and Human Services, Lincoln, NE

Learn about a *College Student Service Learning Respite Curriculum* being used to increase the base of Respite Providers in Nebraska. The project is gaining attention from colleges wanting to identify home-based experiences and enhance student training. Finally, updates to University of Nebraska Medical Center's Employer Engagement project shared at the 2016 ARCH conference will be presented. This session will provide specific information about marketing these innovative projects and how evaluation is being used to demonstrate impact.

E-6 Respite Care Supporting Our Nation's Wounded Warriors

Jed D. Johnson, MSW, MBA, Vice President – Strategic Initiatives, Easterseals national office, Washington, D.C.

Tanya McKee, 2017 Elizabeth Dole Fellow, Gadsden, AL

There are an estimated 5.5 million wounded, ill or injured veterans across the U.S. who rely on family members or friends for day-to-day support. The session will begin with the inspiring story of one veteran caregiver who in their own words shares, "The most important thing for a caregiver is to seek help, this is the most difficult, yet most rewarding, job you will ever have. And you must always move forward, for yourself and for your loved one."

This session will explore the unique aspects of military caregiving and caregivers in comparison to their civilian counterparts. Practical education about different types of respite, training resources and strategies for success will be highlighted.

12:15 – 3:00 pm Lunch and Closing Plenary Session

Policy Panel: The Changing Landscape of State and Federal Policies Affecting Family Caregivers

Currently, Congress is contemplating massive changes to our health care system, drastic restructuring of Medicaid, and substantial cuts to critical safety net programs for the most vulnerable families. At the same time, as the population ages, the need to address financing and availability of long-term services and supports, the shortage of direct service workers, and the critical needs of large numbers of family caregivers becomes even more urgent. We will be

facing some of our greatest challenges in attempting to address these dramatic demographic and policy shifts. As advocates, we need to be prepared to respond quickly to frequent proposed policy changes.

ARCH is proud to present this powerhouse panel of national policy experts to present up-to-the minute news on state and federal aging and disability policy and what it will mean for children and adults with disabilities and chronic illness, older adults and their family caregivers.

Issues to be addressed by the prestigious panel include Lifespan Respite Reauthorization and funding, Medicaid, health insurance, home- and community-based services, direct care workforce issues, caregiver tax credits, state respite and caregiving legislation, and more.

PANELISTS:



Kim Musheno, Association of University Centers on Disabilities, Silver Spring, MD

Kim Musheno is the Director of Public Policy at the Association of University Centers on Disabilities where she works on federal policy and legislative issues that affect people with developmental disabilities and their families. She also provides leadership as Chair of the Consortium for Citizens with Disabilities (CCD), a coalition of more than 100 national disability organizations. Kim also co-chairs CCD Task Forces working on fiscal policy and Education.

Elaine Ryan, AARP, Washington, D.C.

Elaine M. Ryan is the Vice President of State Advocacy and Strategy Integration (SASI) in the Government Affairs Department of AARP. Elaine leads a team of legislative staff who work with our 53 AARP state offices to advance AARP's state advocacy agenda with Governors and state legislators throughout the nation to enable individuals age 50+ and their families to attain and maintain their financial and health security.





Robert Espinoza, PHI, New York, NY

Robert Espinoza is the Vice President of Policy at PHI, the nation's leading authority on the direct care workforce, where he oversees its national policy, research, and communications activities. He designed PHI's #60CaregiverIssues campaign, which is proposing solutions to the country's growing workforce shortage in home care, and generating online conversation among half a million people.

Laura Weidner, National Multiple Sclerosis Society, Washington, DC

Laura Weidner, as Senior Director of Federal Government Relations, leads the National Multiple Sclerosis Society's strategy on federal policy impacting the day-to-day lives of people with MS and their families, including policy related to accessing quality healthcare, long-term services and supports (including family caregiving), durable medical equipment, and Social Security disability benefits. She is a co-chair of the Consortium for Citizens with Disabilities' (CCD) Longterm Services and Supports Task Force, a member of the CCD Board of Directors, a member of the Independence Through **Enhancement of Medicare and Medicaid** Steering Committee, and a board member of Advance CLASS, Inc.



2:45pm Closing Activities and Special Announcements

3:00pm Conference End