



ILLUMINATE RESPITE

2019 NATIONAL LIFESPAN | APRIL 30-
RESPITE CONFERENCE | MAY 2, 2019

Conference Program

Monday Evening, April 29, 2019

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| 4:00 – 7:00 PM | Early Registration/Information Table |
| 5:00 – 7:00 PM | Reception for Lifespan Respite Grantees, Partners, and Guests
Buffalo Grand Hotel
(by invitation only) |

Tuesday, April 30, 2019

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| 8:00 AM - 4:30 PM | Lifespan Respite Grantee and Partner Learning Symposium
(by invitation only) |
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Tuesday Evening, April 30, 2019

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| 3:00 – 8:00 PM | Registration/Information Table |
| 5:00 – 8:00 PM | Welcome and Networking Reception for the 2019 National Lifespan Respite Conference

<i>New York State Wine Tasting and Entertainment</i> |

Wednesday Morning, May 1, 2019

7:00 – 8:30 AM Breakfast

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

8:30 – 9:30 AM **Opening and Welcome**

Jill Kagan, ARCH National Respite Network and Resource Center

Doris Green, New York State Caregiving and Respite Coalition

Greg Olsen, Acting Director, NY State Office for the Aging

Kathy Hochul, Lieutenant Governor of New York (invited)

Nora OBrien-Suric, President, Health Foundation for Western and Central New York

9:30 – 10:00 AM Break and Move to Mezzanine Level

10:00 – 12:15 PM **Caregiver Simulation**



Caregiver Simulation Experience

What better way to understand caregivers, than to spend a few hours in their shoes. This active simulation allows participants to experience a fraction of the challenges caregivers face, day in and day out. Each participant will be assigned a role, and will have tasks, dilemmas and opportunities to navigate throughout the morning. We believe that this experience can develop empathy for caregivers, care receivers and agencies who are involved along the way. We invite you to join us in this simulation as a way of better understanding caregivers, so that we may then effectively engage them.

Wednesday Afternoon, May 1, 2019

12:15 – 1:00 PM Lunch and Networking

1:00 – 2:00 Luncheon Keynote



Andy Goodman
The Goodman Center, Los Angeles, CA
Story Telling as a Best Practice

Andy Goodman is co-founder and director of The Goodman Center, which teaches communications and marketing professionals how to reach more people with more impact. Andy is internationally known for his speeches and workshops on storytelling and has led over 500 trainings for clients including CARE, The Nature Conservancy, Boys and Girls Clubs of America, MIT, Princeton, the Bill and Melinda Gates Foundation, the Robert Wood Johnson Foundation, Bank of America, and many others. He has designed communications curriculum for the College for Social Innovation in Boston as well as for the African Leadership University in Mauritius. He is the author of *Storytelling as Best Practice* and *Why Bad Presentations Happen to Good Causes*.

Since we first began talking to each other, telling stories has been a powerful way to capture attention, engage an audience, and motivate them to act. As we learn more about how our minds work, we're also discovering that stories are intrinsic to decision-making, shape our view of the world, and affect our daily decisions. In his plenary address, "Storytelling as Best Practice," Andy Goodman will explain why storytelling remains the single most powerful communication tool you possess, and he will offer specific ways your organization can use stories to advance your mission.

2:00 – 2:15 Break

2:15 – 3:30 Breakout Session A

A-1 Education and Outreach to Anticipate Caregiver Legal Obstacles in Immigrant Communities

Erin L. Riker, Esq., Center for Elder Law and Justice, Buffalo, NY

This presentation explores access to legal substituted decision-making document preparation as an element of respite provision to family caregivers, particularly those in the immigrant community. Immigrant families are overwhelmingly likely to turn to family caregivers over outside sources and are less likely to have access to substituted decision-making services. Participants will learn how education and outreach regarding substituted decision making can ease a family caregiver's burden.

A-2 Shared Session

A Crisis Plan: An Essential Element to Successful Use of Respite Care

Cordelia Robinson Rosenberg, Ph.D., RN, Professor, University of Colorado JFK Partners, Aurora, CO

Having a Crisis Plan in place is beneficial when families face a behavioral crisis where a family member is a danger to self or others. However, as with many things that are good to have, families do not always do it. This current project seeks to understand barriers and obstacles to a family's development of a Crisis Plan. Presentation will include the Crisis Plan template and guidebook as well as findings from use.

AND

Bringing Emergency Respite Care to Maryland: Lessons Learned and Early Findings

Naomi Duffort, Program Specialist, Respite Care and Project Home, Office of Adult Services, Social Services Administration, Maryland Department of Human Services, Baltimore, MD

Christine Schoenberger, MHS, Business Manager, Maryland Center for Developmental Disabilities at Kennedy Krieger and Maryland Respite Care Coalition, Baltimore, MD

While Maryland has offered respite services across the lifespan for a number of years, it has only recently implemented an emergency respite program through its Lifespan Respite grant. Emergency respite is intended for use when the absence of the primary caregiver is unavoidable and all other options have been exhausted. There are unique challenges implementing a new emergency service such as this. This session describes these challenges and offers guidance for other states that might be interested in offering emergency respite.

A-3 Teaming Up to Support Caregivers at Home and In the Workplace

Sheila Warnock, Founder & President of ShareTheCaregiving, Inc. aka Share The Care™, and Co-chair, NYC Partnership for Family Caregiving Corps, New York City, NY

Gregory L. Johnson, MDiv; SMM, Senior Advisor for Family Caregiver Office of the CEO, EmblemHealth, NYC Caregiver Coalition and NYC Partnership for Family Caregiving Corps, New York City, NY

This session will illustrate the roles that ShareTheCaregiving, Inc. and EmblemHealth's New York City Partnership for the Family Caregiving Corps have taken on broadening their efforts to support diverse caregiving populations. Through the realization of synergies across non-profit, government, institution and corporate borders, these organizations have lengthened their reach and broadened their ability to guide and support the growing numbers of caregivers.

A-4 Respite in Washington: A Beacon of Hope in the Storms of Life

Linda J. Porter, Program Coordinator, Lifespan Respite Washington/PAVE, Tacoma, WA

Amy Knapton Vega, Executive Director, Vanessa Behan Crisis Nursery, Spokane, WA

This dynamic workshop will provide an historical context plus practical considerations while developing respite programming for a variety of population needs. Participants can ask questions and offer suggestions. Providing respite in Washington with a Lifespan Respite approach involves a vital matrix of programs, funding sources, and partners; e.g., state, private, non-profit groups, tribal, brain injury, military, etc. It will show how a program can unfold to become an important community service model.

A-5 Shared Session

Finding True North: The Transition of Project CARE (Caregiver Alternatives to Running on Empty)

Dawn Oakey Gartman, Alzheimer's Specialist/Project CARE Director, NC Department of Health and Human Services, Division of Aging and Adult Services, Raleigh, NC

This presentation will delve into Project CARE's transition to standardizing its care management approach to increase consistency and quality in the delivery of services and supports for caregivers who wish to keep caring for their loved ones at home. It will also discuss approaches taken to quickly ramp up the program to meet its fullest potential and impact statewide.

AND

Revive and Thrive – a Dementia-friendly Fitness Respite Program

Mary McKeown, BA, MA, Former Instructor, Revive and Thrive Program, Merrimack Valley YMCA, Andover, MA

Susan Mcinnis, Co-Founder and Instructor, Revive and Thrive Program, Merrimack Valley YMCA, Andover, MA

This session introduces an illuminating and innovative dementia-friendly wellness and fitness respite program model, Revive and Thrive, developed and implemented by a Massachusetts YMCA. The session also shares findings from a qualitative research study performed by one of the pilot program's interns and co-facilitators -- findings indicating the need for such a program. Session participants will also have the opportunity to explore the need and possibilities for creating such a program in their community.

A-6 Holistic Approach to Caregiving Support

Katy Allen, Director Finger Lakes Caregiver Institute, Lifespan of Greater Rochester, Inc., Rochester, NY

Cindy Steltz, Manager Education and Caregiver Services, Lifespan of Greater Rochester, Inc., Rochester, NY

Join a panel of professionals to learn creative programming ideas, resources, tools and more on how to holistically serve caregivers of people with chronic disease and/or dementia. Learn best practices in using volunteers to build sustainable respite programs. Panel members will present an overview of several respite programs, the how-tos of getting started and how collaboration is the key to success.

3:30 – 3:45 **Break**

3:45 – 5:00 PM **Breakout Session B**

B-1 Latest Trends in Respite Around the World

Kim Whitmore, PhD, RN, Assistant Professor, School of Nursing, University of Wisconsin – Madison, Madison, WI

Catharine Shanahan, Executive Director, Respite Family Services, Windsor, Ontario, Canada

Leslie Atkinson, Executive Director, Safeguards Training for Children and Adult Services, Richmond Hill, Ontario, Canada

Casandra Firman, ARCH Evaluation Staff, ARCH National Respite Network and Resource Center, and T/TA Coordinator, FRIENDS National Center for Community-Based Child Abuse Prevention

Service delivery in every country is influenced by government policy, cultural beliefs, advocacy and resources. Learning from other countries helps us to develop best practices and appreciate the contribution that can be made at the global level to work together to help people with disabilities lead good lives and support their families and loved ones. The American and Canadian ISBA representatives will share the latest information from the International Short Break Association (ISBA) Conference (Iceland).

B-2 Improving the Health and Wellness of Caregivers and Older Adults Through Volunteering

Jessica F Vasquez, Esq, State Program Director-NY, PR, and USVI, Corporation for National and Community Service, Albany, NY

Senior Corps launched two longitudinal studies to look at the health benefits of volunteering in our programs and the impact of our Senior Companions on family caregivers. This session addresses our Longitudinal Study and the health benefits of volunteering in Senior

Corps programs as well as the benefits to the caregivers. We will also share information on the ways to further leverage this national volunteer program locally.

B-3 Shared Session

Future Care Planning Services: How Comprehensive Planning Helps Identify Respite Options

Jen Helmbold, Program Director, Lifespan - Future Care Planning Services, Rochester, NY

Shan Donoghue, Transition Specialist, Lifespan - Future Care Planning Services, Rochester, NY

Planning ahead has many benefits. How can planning uncover “tools” to pay for respite? What “key” factors can be discovered that provide natural resources and/or peace of mind to alleviate caregiver stress? Can planning reduce caregiver burnout and exhaustion thereby diminishing the need for respite? Come see! Learn what we do at Future Care Planning Services and how you can do it too!

AND

Aging in the Community with a Pooled Trust

Rachel Lewis Schepart, Staff Paralegal, Center for Elder Law & Justice, Buffalo, NY

This presentation will provide an explanation of what a Pooled Trust is and how it benefits individuals with disabling conditions of all ages as well as the aging population. The presenter will explain how an individual can remain or become eligible for government benefits, such as Medicaid and Supplemental Security. Attendees will have a better understanding of Pooled Trusts, which allows individuals to remain living in the community with adequate care.

B-4 A Case Study in Organizational Change with Co-Occurring Statewide Long-Term Care Systems Change

Lisa Schneider, Executive Director, Respite Care Association of Wisconsin, Portage, WI

Tricia Lazare, Board President, Respite Care Association of Wisconsin, Portage, WI

Susan Larsen, Chief, Program Integrity and Compliance Section, Bureau of Children's Services, Division of Medicaid Services, Wisconsin Department of Health Services, Madison, WI

The Respite Care Association of Wisconsin (RCAW) and its partners will provide a brief history of the organization and the state Lifespan Respite Program, and how taking a hard look back helped determine how to move forward. A fresh set of eyes and a new perspective set against the backdrop of changes in the long-term care (LTC) delivery

system enabled RCAW to make difficult decisions & implement changes with the goal of meeting the needs of family caregivers while adding value, impact, and increasing our sustainability - with a very limited budget.

B-5 Shared Session

Social Respite Programs for People Living with Dementia: Volunteer-Led, Community-Driven

Lauren Ashburn, MSW, Director of Respite Services & Assistant to Advocacy for the Alzheimer's Association, Western New York Chapter, Williamsville, NY

Rachel Rotach, LMSW, Program & Advocacy Director for the Alzheimer's Association of Western New York, Williamsville, NY

Come learn how an entirely volunteer-led social model respite program can benefit people living with dementia in your own backyard! This session will include an interactive sensory experience on how dementia impacts your senses and why the unique training and management model of these programs by the Alzheimer's Association, WNY Chapter is utilized by volunteers at 20+ locations across the region. Learn how to empower volunteers, develop collaborations with community agencies, and obtain program funding.

AND

"Memory Minders"- Minding Your Loved One's Memory Care

Maureen A. Wendt, President/CEO, The Dale Association, Inc., Lockport, NY

This session is aimed at caregivers who wish to learn the power of social day programming and the benefits it can have on individuals with early to mid-stage dementia. Participants will learn who is appropriate for such programming, how to overcome the barriers and challenges of enrolling your loved one and identify powerful caregiver resources for finding the right social day program that provides social and mental stimulation for people dealing with early memory loss.

B-6 Shared Session

Bringing Nursing Programs and State Agencies Together to Provide Respite for Family Caregivers

Christine McGrane, MS, RN, CNE, RICSNT, Assistant Clinical Professor, College of Nursing, University of Rhode Island, Kingston, RI

Diane C. Martins, PhD, RN, Professor, College of Nursing, University of Rhode Island, Kingston, RI

Lynn P. Blanchette, PhD, RN, PHNA-BC, Associate Dean, Assistant Professor, School of Nursing, Rhode Island College, Providence, RI

The collaboration of multiple agencies and academic partnerships brought forth the creation of a student nurse experience that meets the needs of families in Rhode Island who are caring for loved ones at home and have little opportunity to relinquish their caregiver responsibilities. The families are encouraged to use the provided respite time for self-care activities, which will help them remain energized and able to sustain caring for their loved one at home.

AND

Helping Those Who Care: Partnering to Create an Assistive Technology as Respite Education Training

Tracy Cieniewicz, Sustainability Director, UCP of Huntsville and Alabama Respite, Huntsville, AL

Helping Those Who Care (HTWC) is a respite education training developed by the Alabama Lifespan Respite Resource Network in conjunction with Alabama's AT Act program that introduces aging caregivers to simple assistive technology (AT) solutions for daily living activities as a form of respite. Respite professionals and stakeholders will receive tools to replicate HTWC, including the identification of states' AT Act programs and benefits of partnership.

6:00 – 10:00 PM **Possible Excursion: Dinner Trip to Niagara Falls** *(pre-registration required – there is a pre-paid fee associated with this event)*

Thursday Morning, May 2, 2019

- 7:00 – 8:30 AM** **Breakfast**

- 7:00 – 3:00 PM** **Registration/Information Table**

- 8:30 – 9:30 AM** **Morning Plenary Session: Welcome and Announcements**
ARCH Recognition of Outstanding Innovative Respite Services

9:00 – 9:30 AM

Keynote



Lori Gerhard, Acting Director, Center for Integrated Programs, Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C.

As Acting Director for the Center for Integrated Programs, Ms. Gerhard oversees ACL’s administration of programs and initiatives that serve both older adults and people with disabilities, as well as their families and caregivers. Programs include consumer access and protection and initiatives that promote the use of self-directed and person-centered service models.

She was previously Director for the Office of Consumer Access & Self-Determination, which works in collaboration with other federal agencies to make grants to states to transform Long-Term Service & Support Systems to be more responsive to the needs of people with disabilities, older adults, and their caregivers. The Office of Consumer Access & Self-Determination administers the No Wrong Door System program (ADRC), the Veteran Directed Care program, the Lifespan Respite program, the Inclusive Community Transportation program, the Supported Decision-Making program and the Assistive Technology Act program.

9:30 – 9:45

Break

9:45 – 11:00 Breakout Session C

C-1 Shared Session

Sustaining Innovative Programs with Private Funding: Lessons Learned from a Crisis Nursery

Amy Knapton Vega, MSW, Executive Director, Vanessa Behan Crisis Nursery, Spokane, WA

Come take a walk through a 30-year journey of a grass roots organization that has remained privately funded from its inception. Through trials and tribulations innovative programs and funding efforts have been created. Learn how you can take your dreams and turn them into a reality with a deep impact or simply grow your existing programs to meet increased needs.

AND

Multigenerational Respite: Through the Lenses of Kinship Caregiving

Carrie Savage, Kinship Caregiver Program Manager, Catholic Charities Denver, Denver, CO

Have you met a grandparent raising a grandchild and wondered how they stepped into this role and what their needs are? By attending this presentation, you will learn more about the Kinship caregiver role, what works and what does not work while providing respite care, and creative ways to serve multigenerational families.

C-2 Shared Session

Meeting the Unmet Respite Care Needs of Families of Children with Special Healthcare Needs

Kim Whitmore, PhD, RN, Assistant Professor, School of Nursing, University of Wisconsin – Madison, Madison, WI

Results of a study examining factors associated with unmet respite care needs in 2,518 families of children with special healthcare needs will be presented. Families of children with autism spectrum disorder, whose child has high caregiving demands and functional limitations, and whose family perceives higher family fiscal burden are at highest risk for unmet respite needs.

AND

Creating a Culture of Evidence-Based Respite Care Through an International Knowledge Exchange

Kim Whitmore, PhD, RN, Assistant Professor, School of Nursing, University of Wisconsin – Madison, Madison, WI

Cassandra Firman, ARCH Evaluation Staff, ARCH National Respite Network and Resource Center, and T/TA Coordinator, FRIENDS National Center for Community-Based Child Abuse Prevention

Susan Janko Summers, PhD, Senior Consultant, ARCH National Respite Network and Resource Center

This interactive workshop is a gateway for participants to join an International Knowledge Exchange. The Knowledge Exchange was developed to identify evidence-based and -informed respite practices that can be adapted and applied across countries and cultures. Participants will help build a culture of international learning and research by sharing their experiences and findings—through research, evaluation, or practice—about best respite-care practices for increasing the well-being of caregivers, care recipients, and their families.

C-3 Shared Session

A Light in the Darkness: A Respite Care Journey of Faith, Hope, & Love

Rev. Dr. Cynthia Huling Hummel, Presbyterian Church, USA, Elmira, NY

Rev. Dr. Cynthia Huling Hummel, a Presbyterian pastor, brings a unique perspective to faith-based respite care. She has been a caregiver and a care receiver and a resource to faith communities. Diagnosed with Early-Stage Alzheimer's Disease in 2016, Cynthia joined the Tri-County Faith-Based Respite Coalition to resource congregations in NY's Southern Tier. She is co-founder of "Faithful Friends Respite Care."

AND

How can we best support caregivers/care partners of people with Parkinson's disease?

Nancy Nealon, MSW, Community Development Director, Parkinson's Foundation Greater Rochester, Rochester, NY

Dennis Whitney, Caregiver, Board member, former Board President, Parkinson's Foundation Greater Rochester, Rochester, NY

It's time to shine the light on the caregiver's/care partner's experience as it pertains to Parkinson's disease (PD). PD can create physical, emotional, social and financial stressors for caregivers. This session will explore the unique complexities of this disease, the impact on care partners and specific information about providing caregiver support.

C-4 Shared Session

Shining a Light on Faith Based Communities and their Support of Caregivers

Deaconess Kris Blackwell, Executive Director, Voice of Care, West Chicago, IL

Lois Sheaffer, National Director, REST, Bloomingdale, IL

This panel of faith-based organizations using REST (Respite Education and Support Tools), an evidence-informed training program to train respite volunteers, will give ideas and resources to energize and excite participants to begin their own faith-based respite care programs. The role of faith-based organizations in providing respite care in their communities and beyond will be part of the discussion.

AND

Lighting Up Paul's Place: A Ministry of Faith

Pastor Sandi Perl, Executive Director, The Living Well, Penn Yan, NY

Kimberly Lyons, Outreach Worker, The Living Well, Penn Yan, NY

The Apostle Paul faced many adversities through his life; doubt, fear, and isolation. Yet he overcame it all because he saw the hope in Jesus and became one of the greatest followers and advocates for Jesus Christ. The Living Well strives to connect people to that same hope as they face their own struggles. Paul's Place Respite offered free of charge, with REST trained volunteers, provides another opportunity to come together as a community.

C-5 Shared Session

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

Bonnie Storm, M.S. Ed, Senior Director, Exceptional Family Member Program (EFMP) Respite Care, Child Care Aware of America, Arlington, VA

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

AND

VD-HCBS: The VA and the Local Community Working Together to Help Veterans Live at Home

Susan D. Blevins, Alamo Area Council of Governments, San Antonio, TX

The Veteran-Directed Home and Community Based Services (VD-HCBS) program is a program of the U.S. Department of Veterans Affairs (VA) for self-directed care. This VD-HCBS program is a partnership with the local VA and Alamo Area Council of Governments that works with Veterans who are at risk of long-term placement. This program is designed to keep the Veteran in their homes by providing needed goods and services, such as respite. The Veteran or Veteran Representative hires, supervises, evaluates and pays the employee to provide the requested services.

C-6 Innovative Outreach Methods to Reach Family Caregivers

Meghan Kluth, Director of Respite Initiatives, Easterseals Colorado, Lakewood, CO

Elle Billman, Colorado Respite Care Program Coordinator, Easterseals Colorado, Lakewood, CO

Reaching family caregivers through community outreach is difficult. Caregivers come from all walks of life and there is no single outreach strategy that reaches all effectively. Easterseals Colorado and the Colorado Respite Coalition have developed innovative outreach strategies to help connect families and professionals with needed resources. Explore opportunities for your outreach efforts and the lessons learned from our experience, including adaptable models and creative partnerships.

11:00 – 11:15 Break

11:15 – 12:30 Breakout Session D

D-1 New York Paid Family Leave: Vital Support for Family Caregivers

Tiffany Battles, Empire State Fellow, NYS Workers' Compensation Board, Schenectady, New York

Family care has been shown to improve health outcomes for patients and increase meaning for caregivers. In April 2016, NYS Governor Andrew M. Cuomo took action to make Paid Family Leave a reality and a right for working New Yorkers by signing a law that took effect January 2018. This presentation provides information on NY's landmark Paid Family Leave, emphasizing how it can be used to care for loved ones with a serious health condition.

D-2 Partners in Caregiver Respite Support: A Community-University Case Study

Tiffany R. Washington, PhD, MSW, Assistant Professor, School of Social Work, University of Georgia, Athens, GA

Erin Beasley, B.S.Ed., Director of Operations, Athens Community Council on Aging, Athens, GA

This case study described in this session is about a partnership between a research-intensive university and a non-profit organization focused on aging services to provide respite support to caregivers. Houseguest, a caregiver respite program, was designed using a community-engaged scholarship model of integrating research, teaching, and service.

D-3 Shining a Light on Caregivers- Nancy's House: Caring for Caregivers with a Different Kind of Respite

Elissa Lewin, Founder and Executive Director, Nancy's House, Wyncote, PA

Kim Terry-Koroma, Board Member, Nancy's House, Wyncote, PA

This is an experiential workshop designed so participants can actively engage in exercises that are a part of the unique program that is Nancy's House. Information provided will be applied, practical, and research-based. Program outcomes and supporting research will be discussed.

D-4 Shared Session

Enhancing Respite Quality of Life across Healthcare Settings and Diagnosis

Robin Lombardo, CTRS, MS, CDP, Northeast Regional Director, Music & Memory, Inc., New York, NY

Our experience teaches that non-pharmacological approaches have wide range benefits for everyone. When using personalized music, we promote the recall of memories that inspire a renewed sense of self for participants, fulfillment of purpose for their caregivers and deepened connections for family. Applications include at home, nursing homes, assisted livings, independent livings, hospitals, behavioral health, hospices, home health, adult day, community organizations and intergenerational programs.

AND

Put the Joy Back into Caregiving: A Creative Approach to In-Home Respite

Carol O'Neill, LMSW, Senior Director, In-Home Respite Services, EAC Network, Hempstead, NY

Christine Weber, Program Director In-Home Respite Services, EAC Network, Hempstead, NY

A little bit of fun can go a long way to relieve caregiver stress and anxiety. Every step matters when improving the quality and impact of In-Home Respite Services, from using humor and music to create joyful moments and reduce caregiver stress to keeping caregivers engaged using a strength-based perspective. Tips on technology such as an in-home "assistant" will be shared.

D-5 Shared Session

Providing Respite for Family Caregivers of Persons with ALS

Jennifer Myhre, MSSW, LICSW, The ALS Association, MN/ND/SD Chapter, Minneapolis, MN

Learn how The ALS Association, MN/ND/SD Chapter created a program to provide a respite for family caregivers of persons with ALS. You'll get an overview of how our program works, as well as the steps taken to onboard families. We'll talk about our program successes and challenges, including the barriers we've encountered regarding getting families to use it, and making the service available in our vast service area.

AND

Gaining Confidence as a Family Caregiver

E. Douglas Beach, CEO, Western Reserve Area Agency on Aging, Cleveland, OH

Dr. Beach has served a long career in the aging arena. He now serves as the CEO of the Western Reserve Area Agency on Aging. In this session, he will share his personal experience caring for his mother-in-law at home. Coupled with his passion of educating caregivers about seniors, Dr. Beach touches on his personal journey and offers tools and tips to inspire confidence and self-efficacy to those who want to take care of family and friends at home.

D-6 Shared Session

Variety! The Spice of Life: How to Engage a Variety of Non-Profit Organizations in Respite

Pam Oliason, Program Specialist, Idaho Commission on Aging, Boise, ID

Non-profit organizations offer niches of respite if given funding and technical assistance. Locating organizations with the capacity to imagine offering respite was hard, but we succeeded and funded them with Lifespan Respite grant funds. Examples of respite experiences provided by the funded non-profits include: backpacking trips for caregivers of cancer survivors; five-hour recreation events for families of children with intellectual disabilities--all family members enjoy time with peers; in-home services for caregivers of children with significant medical complications; and respite to lifespan caregivers attending Powerful Tools for Caregivers classes.

AND

Break Rooms Illuminate Respite for Faith Communities

Kathy Mayfield-Smith, Research Associate Professor and Associate Director, Institute for Families in Society, University of South Carolina, Columbia, SC

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

“Break Room” is South Carolina’s new Lifespan Respite grant initiative encouraging faith communities to provide respite to family caregivers during religious services/events by giving care recipients onsite care/activities while caregivers attend congregational activities. It is a simple concept that normalizes respite making it manageable for even small houses of worship. Workshop covers the steps from idea development to implementation, tools used to create the structure (e.g., mini-grant application/instructions, training handbook for grantees), and challenges and successes during this inaugural year.

12:30 – 12:45 PM Break

Thursday Afternoon, May 2, 2019

12:45 – 3:00 PM Lunch and Closing Plenary Session



2020 International Respite Conference Announcement

Kim Whitmore, International Short Break Association (ISBA), ISBA Conference Chair, and Casandra Firman, ARCH

Luncheon Panel: *Seeking Respite, Surviving Burnout: Millennial and Sandwich Generation Caregivers*

PANELISTS:



Gretchen E. Alkema, PhD, Vice President, Policy and Communications, The SCAN Foundation, Long Beach, CA

Gretchen E. Alkema serves as Vice President of Policy and Communications for The SCAN Foundation and her professional and personal interests overlap with improving the quality of life for older adults and their caregivers. Prior to joining the Foundation, she was the 2008-09 John Heinz/Health and Aging Policy Fellow and an American Political Science Association Congressional Fellow, serving in the office of Senator Blanche L. Lincoln (D-AR).

**Rachel Hiles, Caregiver Advocate, Kansas City, MO,
with The SCAN Foundation's *Do YOU give a care?*
Campaign**

Rachel Hiles, 31, is one of 10 million Millennial caregivers in America. Growing up, Rachel's grandmother played a huge role in raising her and championing her career aspirations. Rachel worked as a paid caregiver during undergrad, learning how to support people with disabilities to live independently at home and then continued working in the developmental disability field for nearly a decade. After a series of falls landed her grandmother in the hospital, the tables shifted. As her grandmother's primary caregiver in Kansas City, Mo., Rachel works to support her grandma's quality of life while pursuing her own future goals using practical strategies to make sure that they both have the supports they need.



Rachel knows her "day-to-day" doesn't look like a typical Millennial's, which is why she continues to share her story to raise awareness and support other caregivers.



C. Grace Whiting, J.D., President and CEO, National Alliance for Caregiving, Washington, D.C.

C. Grace Whiting, J.D., is the President and Chief Executive Officer at the National Alliance for Caregiving (NAC), where she continues her tenure from previous roles including Chief Operating Officer and the Director of Strategic Partnerships. Grace led the launch of the Caregiving in the U.S. 2015 report with AARP and directed the first national study of rare disease caregiving with Global Genes. She has contributed to several national reports on caregiving, including Cancer Caregiving in the U.S. with the National Cancer Institute and Cancer Support Community, and Dementia Caregiving in the U.S. with the Alzheimer's Association. She has spoken on caregiving at national and international conferences, including the 7th International Carers Conference and at multiple national summits at the National Institutes of Health. Grace has also served as a resource to major media on the topic of caregiving and aging, including C-SPAN, *The Wall Street Journal*, *Time Magazine*, *Oprah Magazine*, *Women's Health Magazine*, and *Kiplinger's Retirement Report*. In addition to her leadership role at NAC, Grace represents the U.S. on the Governing Board of the International Alliance for Carer Organizations.

2:45 – 3:00 PM

Wrap-Up and Conference End