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16th National Lifespan Respite Conference

October 7 – 9, 2014 ~ Nashville, TN

TENNESSEE
RESPITE
COALITION



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Respite
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16th National Lifespan Respite Conference

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Welcome to Nashville and the 16th National Lifespan Respite Conference

Welcome to the 16th National Lifespan Respite Conference and to Nashville, best known as Music City! The conference theme, *Get in Tune with*



Respite, aptly reflects the great musical culture centered here and challenges conference attendees to learn and share how respite can create harmony for families in caregiving situations.

A lot to sing about this year

There is a lot to sing about this year! 2014 is especially noteworthy as we celebrate the 5th Anniversary of the federal Lifespan Respite Program and 17 years since Oregon passed the first state Lifespan Respite legislation in 1997. As a result, new state respite coalitions have emerged and 32 states and the District of Columbia have received federal Lifespan Respite grants to better coordinate and streamline respite at the state level, making it easier for families to find and use respite. These efforts have spawned unprecedented collaboration and innovative best practices in the field. Significant awareness has grown up around the respite needs of the nation's 65 million family caregivers, but we still have a long way to go!

Economically challenging times in recent years have forced us to think more creatively about engaging and sustaining new partners to support families – whether these are with non-traditional service providers, volunteer or faith-based initiatives, university students, consumer-directed programs, or employers who are exploring ways to serve the escalating number of working family caregivers. As states shift to managed care for providing long term services and supports, we have had to educate ourselves about how to work with ever-changing health care and social service systems. Increasingly, we are looking to peers, friends, neighbors and our local communities to offer a helping hand. And we have been meeting these challenges head on! This conference will showcase new ways of supporting families, innovative best practices in service delivery and financing, research to improve and expand respite, and community building and networking.



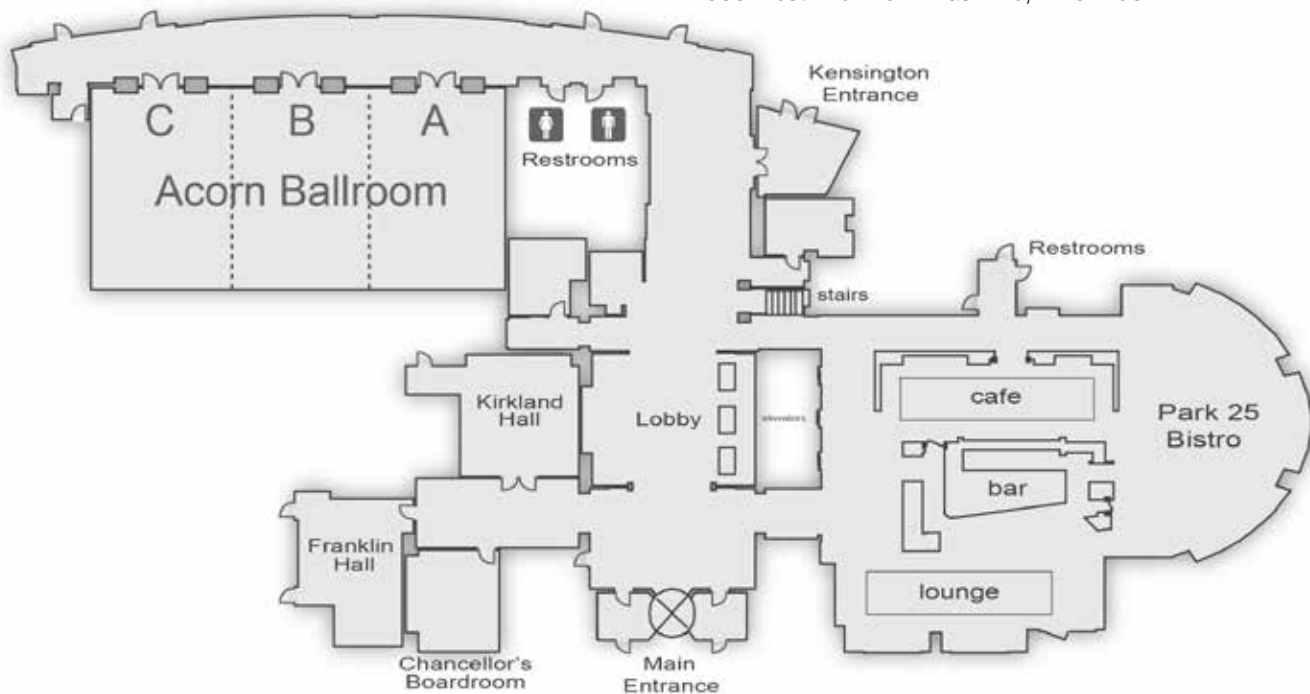
Take advantage of everything this conference and Nashville have to offer and let's make some great music together!



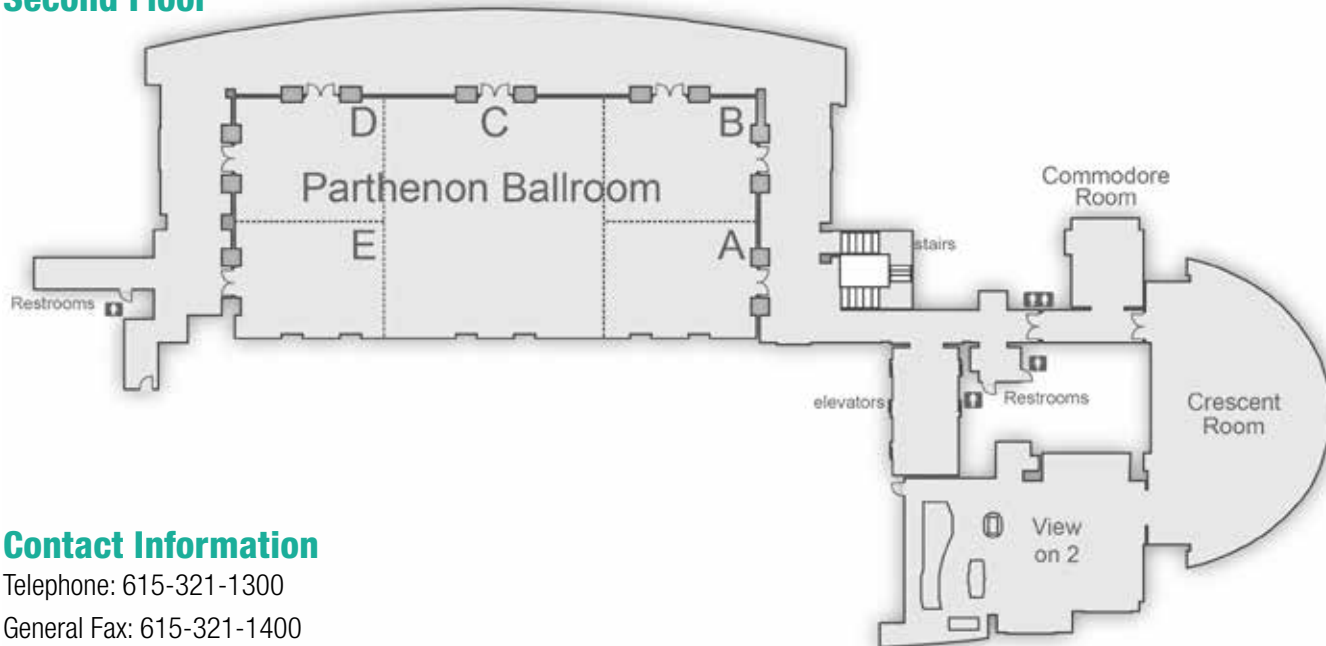
Nashville Marriott at Vanderbilt University

2555 West End Ave. • Nashville, TN 37203

First Floor



Second Floor



Contact Information

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2 16th National Lifespan Respite Conference

Overall Conference Schedule

Tuesday, October 7 – National Conference Reception

3:00pm – 7:30pm	Registration	Second Floor
6:00pm – 9:00pm	Welcome Reception	Crescent Room (Second Floor)

Wednesday, October 8 – Conference, Day One

7:30am – 5:00pm	Registration/Information Table	Second Floor
7:30am – 9:00am	Continental Breakfast	Parthenon Ballroom (Second Floor)
9:00am – 9:30am	Opening and Welcome	Parthenon Ballroom
9:30am – 10:30am	KidBilly Music	Parthenon Ballroom
10:30am – 11:00am	Break	
11:00am – 12:15pm	Workshops – Session A	See Full Schedule for Workshop Rooms
12:15pm – 12:45pm	Lunch Buffet	Parthenon Ballroom
12:45pm – 1:45pm	Keynote Speaker – Sharon Lewis	Parthenon Ballroom
1:45pm – 2:15pm	Break	
2:15pm – 3:30pm	Workshops – Session B	See Full Schedule for Workshop Rooms
3:30pm – 3:45pm	Break	
3:45pm – 5:00pm	Workshops – Session C	See Full Schedule for Workshop Rooms
6:00pm – 9:00pm	Charter Bus to Downtown Nashville <i>(Bus Leaves Every Half Hour)</i>	First Floor (Back of Hotel)

Thursday, October 9 – Conference, Day Two

7:30am – 5:00pm	Registration/Information Table	Second Floor
7:30am – 9:00am	Breakfast Buffet	Parthenon Ballroom (Second Floor)
9:00am – 9:45am	Keynote Speaker – Leisa Easom	Parthenon Ballroom
9:45am – 10:45am	Lifespan Respite Plenary Panel	Parthenon Ballroom
10:45am – 11:15am	Break	
11:15am – 12:30pm	Workshops – Session D	See Full Schedule for Workshop Rooms
12:30pm – 1:00pm	Lunch Buffet	Parthenon Ballroom
1:00pm – 2:15pm	Community Innovations Plenary Panel	Parthenon Ballroom
2:15pm – 2:45pm	Break	
2:45pm – 4:00pm	Workshops – Session E	See Full Schedule for Workshop Rooms
4:00pm – 4:30pm	Closing Ceremony and Door Prizes	Parthenon Ballroom
5:00pm – 6:00pm	Reception for Lifespan Respite Grantees and Partners	Crescent Room



*Please visit our exhibit tables from 8am to 5pm on Wednesday, October 8, and Thursday, October 9.
Exhibitors located outside the Parthenon Ballroom on the Second Floor.*



Friday, October 10 – Lifespan Respite Grantee and Partner Learning Symposium

(By invitation only for Lifespan Respite Grantees and Partners. Separate registration required)

7:30am – 8:30am	Registration and Continental Breakfast	Crescent Room
8:30am – 3:00pm	Presentations and Interactive Discussion	Crescent Room



Conference Tracks

To assist you in planning your conference experience, we have categorized breakout sessions by the following tracks that we hope will help you select presentations that are most meaningful for you.



Business Development

Successful programs are gaining respect in the business and policy world as efficient and cost-effective. It is imperative that we learn from and replicate successful models that have improved administrative as well as service capacity as we move ahead in meeting growing numbers of family caregivers.



Evaluation and Research

As service providers and caregivers make a case for respite availability and funding, we need to demonstrate the effectiveness of respite services through data collection and analysis. Research also provides understanding of the health and well-being of family caregivers. This track presents findings from evaluations of lifespan respite activities, respite models, technologies and interventions to assist care recipients and their family caregivers, and the latest science on stress.



Family Caregivers

This track is primarily geared to family caregivers and those who work with family caregivers who want to learn more about caregiving, about cultural differences among caregivers, or to learn new strategies and activities to promote wellness.



Advocacy and Networking

Connecting with others in your state and from around the country is essential for promoting respite and the needs of family caregivers. Collaboration is also important in building strong respite coalitions, in advancing coordinated systems of respite options, in strengthening cross-agency partnerships, and for reaching underserved populations. These sessions will explore use of media, strategic planning, and other strategies.



Service Delivery Options

This track highlights models in respite training for providers and those who assist family caregivers; service delivery options including voucher programs and consumer-directed respite, planned and emergency respite, and volunteer respite; and explores innovations in respite and managed care, respite registries and online technologies. Respite for veterans and military families, for underserved populations across the lifespan, and non-traditional approaches to respite will also be explored.

Some sessions that fall into the above tracks may also be relevant in a Lifespan Respite Track. These sessions may be of particular interest to Lifespan Respite grantees and their partners.



Lifespan Respite

Through the federal Lifespan Respite Program, the US Administration for Community Living/Administration on Aging awards competitive grants to state agencies in partnership with state respite coalitions and others to develop statewide coordinated systems of community-based respite services for family caregivers of children and adults with special needs. This track will showcase best practices of these Lifespan Respite grant activities.

Chat with Us on Twitter at #Respiteconf



Tweet #RespiteConf

Come chat with us on Twitter during the conference. We encourage you to share your reactions to conference plenary sessions, keynote addresses and workshops by chatting on Twitter at #RespiteConf. Network and engage with colleagues and presenters by posing questions, offering insights and information from your own experience, and sharing new resources and even photos! We welcome all Twitter chatter!



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Congratulations to the Tennessee Respite Coalition!

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Can a Special Needs Trust Help You?


VistaPoints
The Special Needs Trust & Resource Center

Special Needs Trusts safeguard personal assets and provide for services or items that public benefits do not cover – all without jeopardizing eligibility for government benefits and public assistance programs.

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Telephone: (615) 313-4700 Toll-free: 1-800-270-1349





Tuesday, October 7 - National Conference Reception

3:00pm – 7:30pm Registration _____ Second Floor
6:00pm – 9:00pm **WELCOME RECEPTION** _____ Crescent Room (Second Floor)

As the conference theme says, let's *Get in Tune with Respite!* Join us for some wonderful music from local musicians – Chris Walters, Michael Rinne, and Chris Brown – as well as personal stories from Tennessee caregivers about the effect respite has on their lives. This reception will give you the chance to catch up with your friends and colleagues from around the country. Heavy hors d'oeuvre will be served. Drink tickets will be provided and a cash bar after that.

Wednesday, October 8 - Conference, Day One

7:30am – 5:00pm Registration/Information Table _____ Second Floor
7:30am – 9:00am Continental Breakfast _____ Parthenon Ballroom (Second Floor)
9:00am – 9:30am **OPENING and WELCOME** _____ Parthenon Ballroom

- *Jennifer Abernathy, Executive Director, Tennessee Respite Coalition*
- *Jill Kagan, Director, ARCH National Respite Network and Resource Center*
- *The Honorable Bo Mitchell, Tennessee State Representative (District 50) and Metro Nashville Council (District 35)*

9:30am – 10:30am **KIDBILLY MUSIC: Team Building through Song** _____ Parthenon Ballroom

Award-winning song writers, Billy Kirsch and team, will lead conference attendees in an interactive and dynamic song writing experience to reflect the passion and need for respite among the nation's family caregivers. Participants will rediscover their creativity to become more innovative and engaged in their work and we will leave with new messaging ideas for respite.

The KidBilly song-writing team has enjoyed Grammy awards, Emmy and Tony nominations, Country Music Association awards, multiple top 10 and number one hit songs recorded by singers such as Wynonna Judd. Credits include appearances on The Tonight Show, David Letterman, and recordings with artists Keith Urban, Ray Charles, Kenny Rogers, Shania Twain, Martina McBride and many more.



 *Please visit our exhibit tables from 8:00am to 5:00pm outside the Parthenon Ballroom.* 

Wednesday, October 8 – Conference, Day One (cont.)

10:30am – 11:00am BREAK

11:00am – 12:15pm **WORKSHOPS – Session A**



A-1 Shared Session:

Tracks: Business Development and Lifespan Respite

Room: Acorn A

How to Utilize College Interns Effectively to Benefit a Respite Program

- *Lynn Easterwood, Social Worker and Volunteer Coordinator, Hospice of North Alabama, Huntsville, AL*

An excellent resource for respite programs is utilizing college student interns. During the presentation, participants will gain knowledge on how to provide an exceptional intern learning experience for the student while benefiting a respite program. Interns can provide valuable services in developing a program, recruiting respite workers and offer respite services as needed. The intern learns tremendously about the service population when assisting with a respite program and the specific needs of the caregivers.

Traveling “The Long and Winding Road” “With a Little Help from My Friends”

- *Joan Kelly Rafferty, OTR/L, Project Coordinator, Massachusetts Lifespan Respite Coalition and Co-Director, The Respite Project, N. Waltham, MA*

This workshop will describe The Respite Project (TRP), a small scale model of respite provision that utilizes college students earning credit, thus providing services at no cost to families. Presenters will discuss a number of “no cost” strategies used to implement this project. Through case examination, presenters will identify steps taken to create a business plan that has secured funding for replication of TRP with a Massachusetts state agency and the Massachusetts Lifespan Respite Coalition.



A-2 A Model of Health for Family Caregivers

Track: Evaluation and Research

Room: Acorn B

- *Flo Weierbach, PhD, MPH, RN, Assistant Professor, East Tennessee State University College of Nursing, Johnson City, TN*

The presentation focuses on family caregivers and their health and on a new model of caregiver health which was developed by the presenter. The development and empirical testing of the Caregiver Health Model and findings from the initial study will be discussed. Caregiver health was measured using the NIH Global Health PROMIS instrument. The presentation concludes with implications for caregivers and providers and future studies using the Caregiver Health Model.



Tweet #RespiteConf



Please visit our exhibit tables from 8:00am to 5:00pm outside the Parthenon Ballroom.



Wednesday, October 8 – Conference, Day One (cont.)



A-3 Shared Session:

Track: Service Delivery Options

Room: Acorn C

How the Family Lifestyle Model Provides an Alternative to Traditional Respite Care

- *Barry O'Neill, Marketing and Promotions Manager, MillarRich, Nashville, TN*

MillarRich is recognized by the TN Department of Intellectual and Developmental Disabilities (DIDD) as a 3-star care agency because of its high standards, use of technology and constancy of care. MillarRich is now extending its unique Family Lifestyle Model to respite and would like to share the advantages of caring for your family members in this way.

Crisis Respite Services in Tennessee

- *Melissa Sparks, RN, MSN, Director, Crisis Services and Suicide Prevention at Tennessee Department of Mental Health and Substance Abuse Services, Nashville, TN*

This presentation is designed to raise awareness of the benefits of using emergency respite services to temporarily remove an individual experiencing behavioral health symptoms from a situation which may be exacerbating a crisis episode. In Tennessee, there are four crisis respite providers offering voluntary, short-term stabilization, accessible to individuals 18 and older, 24 hours per day, 7 days per week, 365 days per year (24/7/365) in a non-hospital based facility.



A-4 Caregivers: Our Inner Strengths

Track: Family Caregivers

Room: Parthenon D

- *Pam Bryan, Certified Brain Injury Specialist, Family Caregiver, Madison, TN*
- *Jean Doster, Director, Traumatic Brain Injury Program, Nashville, TN*

As a caregiver, it is beneficial to set realistic goals, trust your instincts, love and believe in yourself, maintain your health, keep your life in balance, take a break/respite, accept help, and know that you are not alone. This presentation will help family caregivers understand how long term respite can help achieve their inner strengths, accept the help of respite providers, and the importance of taking care of themselves as well as their loved ones.



A-5 Shared Session:

Tracks: Advocacy and Networking and Lifespan Respite

Room: Parthenon E

Helping Caregivers through the Balanced Incentive Program

- *Joyce Pohlman, Grant Coordinator, Texas Department of Aging and Disability Services, Austin, TX*

The Balanced Incentive Program (BIP) was created in 2010 as part of the Affordable Care Act, with the goal of reducing Medicaid spending on institution-based Long Term Services and Supports (LTSS). Participation in BIP gave states an opportunity to receive millions of dollars in increased funding for community-based LTSS. This workshop will provide an overview of the BIP and how some states have used this program to increase access to caregiver services, including respite. Participants will discuss how BIP is being implemented in their state and how it is supporting caregivers.

Wednesday, October 8 – Conference, Day One (cont.)

In Tune with Respite: One State's Experience Integrating Respite into Other Healthcare Initiatives

- *Kathy Mayfield-Smith, SC Respite Coalition, Columbia, SC*

The SC Respite Coalition will share one state's experience building partnerships across the lifespan to strategically "get their state's key stakeholders in tune with respite." Presentation will show how we are working to integrate a respite/caregiver focus into other systems change efforts (e.g., healthcare reform, statewide long-term care initiatives). Participants will explore opportunities for infusing respite into key discussions and short and long-range initiatives in changing healthcare environments prompted by the Affordable Care Act (ACA) and other external forces.

12:15pm – 12:45pm LUNCH BUFFET _____ Parthenon Ballroom

12:45pm – 1:45pm **KEYNOTE SPEAKER** _____ Parthenon Ballroom

- *Introduction: Jim Shulman, Executive Director, TN Commission on Aging and Disability, Nashville, TN*
- *Sharon Lewis, Principal Deputy Administrator, Administration for Community Living, and Senior Advisor to the Secretary on Disability Policy, US Department of Health and Human Services, Washington, DC*



Sharon Lewis was appointed Principal Deputy Administrator of the Administration for Community Living and Senior Advisor to the HHS Secretary on Disability Policy in November 2013. Prior to this, Sharon was the Commissioner of the Administration on Intellectual and Developmental Disabilities. Well known as an effective advocate, Sharon has a proven track record in championing disability issues. She has been particularly focused on ensuring that the perspective of people with disabilities and their families are central to program and policy efforts.

Sharon has worked in disability policy for more than 15 years at local, state, and national levels. She is the recipient of numerous awards, including the 2010 Distinguished Leadership in National Disability Policy Award and the Consortium for Citizens with Disabilities Chairman's Award. A native of Michigan, she is a parent to three daughters, including one with a disability.

1:45pm – 2:15pm BREAK

2:15pm – 3:30pm **WORKSHOPS – Session B**



B-1 Caregivercentral.org – Providing Earlier, High-quality Intervention via the Internet

Track: Business Development
Room Acorn A

- *Mary Ellen Grant, Chief Executive Officer, Share the Care, Inc., Winter Park, FL*
- *Tamika Harris, Chief Operating Officer, Share the Care, Inc., Winter Park, FL*

This session will provide the history of the CaregiverCentral.org model, from being chosen as one of the 14 Innovative Programs for Family Caregivers funded in the nation by the Harry and Jeanette Weinberg Foundation to its becoming a reality in Central Florida. CaregiverCentral consists of a coded caregiver self-assessment tool which moves families toward vetted providers in the community. Results and replication will be discussed.

Wednesday, October 16 – Conference, Day One (cont.)



B-2 Respite for Families Affected by MS: Models of Program Delivery and Advocacy Partnerships to Serve Younger Adults with Disabilities

Tracks: Advocacy and Networking and Lifespan Respite

Room: Acorn B

- *Laura Weidner, Esq., Director, Federal Government Relations, National Multiple Sclerosis Society, Washington, DC*
- *Marva Serotkin, MPH, President and CEO, The Boston Home, Boston, MA*
- *Amy Watkins, Client and Community Programs Manager, National Multiple Sclerosis Society, Connecticut Chapter, Hartford, CT*

The Lifespan Respite Care Program (LRCP) is to serve individuals and families regardless of age or disability. Since multiple sclerosis (MS) is typically diagnosed between the ages of 20 and 50, it is an important population for states to involve when structuring and implementing their Lifespan Respite programs to ensure that the needs of younger adults with disabilities are met. The workshop will feature two respite models effectively used by families affected by MS—including a wellness day program partially funded by Lifespan Respite in Massachusetts. The workshop will also discuss some states' successful advocacy and program delivery partnerships with local National MS Society chapters to show how connections can magnify impact and guarantee that the LRCP fulfills its promise of serving across the lifespan.



B-3 Respite Relief Using Special Needs Trusts

Track: Service Delivery Options

Room: Acorn C

- *Darlene Kemp, Executive Director, Vista Points Special Needs Trusts, Mount Juliet, TN*

Proving the best quality of life requires informed decisions. Vista Points, Inc. provides the resources to properly manage special needs trusts and helps you receive respite care for your loved one. Topics to be discussed are:

- How can a trust assist my loved one living with a disability or chronic illness?
- How is a special needs trust established?
- How do I use a special needs trust to pay for services/items that government benefits do not cover?
- What happens to the special needs trust when I die?



B-4 Shared Session:

Tracks: Service Delivery Options and Lifespan Respite

Room: Parthenon D

Turning Obstacles into Opportunities: Reinventing Respite Programs with a Unique Service Model

- *Melissa McQuilkin, MSW, Social Services Program Administrator/Respite Director, Broward Children's Center, Pompano Beach, FL*
- *Jacqui Mogavero, MBA, Operations Officer, Broward Children's Center, Pompano Beach, FL*

This session will discuss how respite programs can “think outside the box” to offer their services in new, creative, and flexible ways to meet common needs and barriers for families with special needs children, such as transportation, guilt, trust, cost, medical needs, and typical siblings. By adding new

Wednesday, October 8 – Conference, Day One (cont.)

elements to the service delivery model, respite programs can make themselves unique among other services, helping to draw in potential funders, competitive staffing applicants, and families formerly hesitant or unable to access services.

Collaboration – The Solution to Respite, Recreation, and Increasing Healthcare Providers in Your State

- *Lynn Robinson, President and CEO, Easter Seals Colorado, Lakewood, CO*
- *Meghan Baskett, Project Manager, Colorado Respite Care Project, Lakewood, CO*

Developing creative and affordable respite care models is crucial to addressing the needs of millions of families with special needs. The Discovery Club program, created by Easter Seals Colorado, offers a unique model that provides low or no cost respite to families and training opportunities to future health care professionals. The model can be easily adapted to all types of communities through collaboration and leveraging of resources.



B-5 Measuring Impact: Evaluation Lessons from Massachusetts Lifespan Respite Coalition Programs

Tracks: Evaluation and Research and Lifespan Respite

Room: Parthenon E

- *Emily Kearns, President of Kearns Consulting, Massachusetts Lifespan Respite Coalition Board of Directors, Andover, MA*
- *Amy Korstvedt Nazaire, Project Director, Massachusetts Lifespan Respite Project, and Regional Director of Family Support and Children's Services, Massachusetts Department of Developmental Services, Northeast Region, Hathorne, MA*

This interactive workshop session explores evaluation strategies for measuring respite program impact. Participants will have the opportunity to learn from the lessons of the Massachusetts Lifespan Respite Coalition's evaluation of its 10 mini grantees, and to begin to develop evaluation strategies for their own programs. Specific tools and protocols for data collection will be discussed and participants will exchange lessons from their evaluation efforts as well.

3:30pm – 3:45pm

BREAK

3:45pm – 5:00pm

WORKSHOPS – Session C



C-1 TABS – Tennessee Adult Brothers and Sisters of People with Disabilities

Track: Advocacy and Networking

Room: Acorn A

- *John Donovan, Coordinator, TABS, Nashville, TN*
- *Alicia Fitts, Executive Committee, TABS, Brentwood, TN*
- *Sherry Dunham, Executive Committee, TABS, Knoxville, TN*

This session will be an introduction to the support group for Tennessee adult siblings who have a brother or sister with a disability. This group hosts an annual conference to discuss trends, news, and socialize with other siblings, professionals, and government officials with an interest in sibling support. It also meets regional meetings on the third Thursday of the month, aptly called "TABS Third Thursday." TABS is associated with National Sibling Leadership, The Arc USA and The Arc Tennessee, Tennessee Council on Developmental Disabilities, and others.

Wednesday, October 8 – Conference, Day One (cont.)



C-2 Shared Session:

Track: Service Delivery Options

Room: Acorn B

Sustainable Volunteer Respite Models Are Music to Our Ears

- *Lois Sheaffer-Kramer, REST Program Director, REST Program, Bloomingdale, IL*
- *Kelly Fitzgerald, REST Program Manager, REST Program, Bloomingdale, IL*

This session will explore four unique volunteer models that utilize trained volunteers to create networks of support through respite for caregivers. The models of support will include faith-based; hospital/hospice; university/college; and veteran/military families.

Volunteer Respite Program to Benefit Family Caregivers

- *Clare Farless, B.S., Family Caregiver Coordinator, Upper Cumberland Area Agency on Aging and Disability, Cookeville, TN*

This session will provide an explanation of how one Tennessee region's Area Agency on Aging and Disability developed a volunteer respite program using the REST program model.



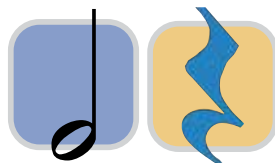
C-3 Orchestrating Partnerships and Leveraging Resources to Create and Sustain Respite Opportunities

Track: Business Development

Room: Acorn C

- *Brenda Reece, Executive Director, High Country Caregiver Foundation, Family Caregiver Specialists, High Country AAA, Boone, NC*

We all know that most of our frail elderly and disabled adults are cared for by family members, friends, neighbors and other loved ones. For some, it's by choice. For most it's a necessity. We simply do not have the necessary infrastructure and funds to provide professional caregivers for everyone who needs them. Find out how to access the community assets in your area to leverage funds and in-kind donations to create respite opportunities.



C-4 Using Online Training to Build a Caregiver-savvy Ensemble of Professionals

Tracks: Service Delivery Options and Lifespan Respite

Room: Parthenon D

- *Alicia Blater, M.S., APR, Project Director, North Carolina Lifespan Respite Project, Raleigh, NC*
- *Linda Kendall Fields, M.Ed, Project Specialist, North Carolina Lifespan Respite Project, Raleigh, NC*

North Carolina Lifespan Respite Program staff will present and discuss the state's new web-based, on-demand training modules titled "Planning and Using Respite: Working with Family Caregivers across the Lifespan." As a strategy for embedding a respite and caregiver focus in the state's long-term services and support system, this five-part series of modules is aimed at Options Counselors and other human service professionals who work with family caregivers across the lifespan. Modules include: 1) Introduction: Caregivers, Caregiving and Respite; 2) Engagement and Screening; 3) Assessing Caregivers; 4) Planning Principles and Tools; and 5) Planning Examples and Following Up.

Wednesday, October 8 – Conference, Day One (cont.)



C-5 Using BridgingApps in a Group Respite Program

Track: Evaluation and Research

Room: Parthenon E

- *Kelly Kaleta, Parent Night Out Respite Coordinator, Easter Seals Greater Houston, Bellaire, TX*
- *Linda Latimer, Respite Director/Housing Director, Easter Seals Greater Houston, Bellaire, TX*

In this presentation, we discuss the results of using the BridgingApps program within a group respite environment (Parent Night Out). Parent Night Out (PNO) serves teens with Autism Spectrum disorder for 3 hours on a weekly basis. Most teens (8 out of 10) who participated in the BridgingApps program showed marked improvement in the defining criteria that characterize social cognition. These data suggest that using assistive technology, within a group respite environment, can be a powerful tool in improving social cognition.

6:00pm – 9:00pm

DINNER ON YOUR OWN IN MUSIC CITY

Charter Bus to Downtown Nashville _____ 1st Floor (Back of Hotel)
(Bus Leaves Every Half Hour)

While here in Music City, we wanted to give you the full Nashville experience! Join us for a complimentary bus ride downtown to hit the Honky Tonks. The bus will depart every half hour from the back of the hotel and take you to “Lower Broad.” From here, you can take your pick of the many dinner, bar and music options. Map will be provided with some highlighted spots you won’t want to miss. It will be your responsibility to get back to the hotel. We will provide you with information for several cab options to return to the hotel.



Photos Courtesy of Nashville Convention & Visitors Corporation

Thursday, October 9 - Conference, Day Two

7:30am – 5:00pm	Registration/Information Table _____	Second Floor
7:30am – 9:00am	BREAKFAST BUFFET _____	Parthenon Ballroom (Second Floor)
9:00am – 9:45am	KEYNOTE SPEAKER _____	Parthenon Ballroom

- *Introduction by Jill Kagan, Program Director, ARCH National Respite Network and Resource Center*
- *Leisa R. Easom, Ph.D., R.N., Executive Director, Rosalynn Carter Institute for Caregiving, Georgia Southwestern State University*



Leisa R. Easom, PhD, RN, is the Executive Director of the Rosalynn Carter Institute for Caregiving (RCI) and Pope Eminent Scholar at Georgia Southwestern State University (GSW). The mission of the RCI is to establish local, state, national and international partnerships committed to building quality long-term, home and community-based services for caregivers in the promotion of caregiver health, skills, and resilience.

Certified in gerontology, Dr. Easom focuses her program of research on caregivers (military and dementia), end-of-life issues, aging, and health promotion in rural areas of the United States. She has been the recipient of many awards including Teacher of

the Year Award at GSW and was selected as a Helene Fuld Scholar recipient for the American Association of Colleges of Nursing (AACN) Leadership program. Dr. Easom serves on the Medical Assisting Board for South Georgia Technical College, on the Caregiving Advisory Panel for the U. S. Administration on Aging, the ARCH Expert Panel on Respite Research, and the Carter Center Task Force for Mental Health. She was recently selected as a “Reynolds Center of Geriatric Nursing Excellence Distinguished Scholar in Aging”.

9:45am – 10:45am	Lifespan Respite Plenary Panel _____	Parthenon Ballroom
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Hitting the High Notes with Lifespan Respite: Progress at the Five-Year Point

- *Moderator: Jill Kagan, Program Director, ARCH National Respite Network and Resource Center*
- *Greg Link, Administration for Community Living, Administration on Aging, US Department of Health and Human Services, Washington, DC*
- *Sharon Johnson, Program Coordinator, Children and Family Services, Lifespan Respite Program and Disabled Persons and Family Support Program, Nebraska Department of Health and Human Services, Lincoln, NE*
- *Peggy Spaulding, State Unit on Aging Program Specialist, Office of Community Access and Independence, Colorado Department of Human Services, Denver, CO*
- *Tabitha Satterfield, Aging Program Coordinator, Tennessee Commission on Aging and Disability, Nashville, TN*

Since 2009, the Administration for Community Living/Administration on Aging has funded 32 states and the District of Columbia to build Lifespan Respite programs. States have used grant funds to build coordinated systems of community-based respite for family caregivers caring for persons with disabilities or chronic conditions of any age. This session will explore the innovative accomplishments of state grantees and their state respite coalition partners five years after the first states were funded and will explore future directions for the program.



Please visit our exhibit tables from 8:00am to 5:00pm outside the Parthenon Ballroom.



Thursday, October 9 – Conference, Day Two (cont.)

10:45am – 11:15am BREAK

11:15am – 12:30pm **WORKSHOPS – Session D**



D-1 Respite Care: Exploring Managed Care Solutions

Track: Service Delivery Options

Room: Acorn A

- *Melinda Henderson, MD, National Medical Director, United Healthcare, Brentwood, TN*

Long-term services and supports are increasingly being provided under a managed care environment. This workshop will explain what this change means for family caregivers, with specific regard to respite. The workshop will provide an overview of services offered through one Managed Care Organization (MCO) and its policies regarding respite care. It will also provide direction on how families and others can work with MCOs to advocate for respite care availability.



D-2 Caregiving: Nashville Public Television's Aging Matters Initiative

Track: Advocacy and Networking

Room: Acorn B

- *Jo Ann Scalf, Education Director, Nashville Public Television, Nashville, TN*
- *LaTonya Turner, Producer, Nashville Public Television, Nashville, TN*

Join Nashville Public Television as we explore the many factors of being a caregiver through our NPT Reports: Aging Matters program "Caregiving." Are you prepared to be a caregiver? Do you know where to turn for help? Can your family afford the costs of long term care? And what is the plan for your own needs? Join an engaging screening and discussion facilitated by NPT producer LaTonya Turner and education director Jo Ann Scalf.



D-3 Caring Too Much: Impact of Stress on Brain Pathways of Caregivers

Track: Evaluation and Research

Room: Acorn C

- *Dr. Stephen D'Amico, MD, CMD, FAGGS, Franklin, TN*
- *Dr. Annita Kerr-D'Amico, Franklin, TN*

Caregiving involves both stress and anxiety. Stress stimulates a metabolic alert dance in the brain and although the brain is well designed to respond to stress, it is not built to carry chronic stress. This presentation will discuss the different ways caregiving stress impacts and changes the brain. As the brain seeks homeostasis, the limbic system shifts neuron networks in an attempt to protect the brain from the caustic effects of hyperactivity caused by anxiety. Professionals assisting caregivers must understand how to communicate with those under chronic stress.



Tweet #RespiteConf



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Thursday, October 9 – Conference, Day Two (cont.)



D-4 Shared Session:

Tracks: Business Development and Lifespan Respite

Room: Parthenon D

Sustaining Respite Collaborations with the Help of Technology

- *Sharon J. Johnson, Program Coordinator, Nebraska Department of Health and Human Services, Lincoln, NE*

Hear straight talk about Nebraska's efforts to improve coordination and dissemination of service delivery between various respite programs and funding streams using technology. We will spend time discussing the challenges of long-term sustainability efforts undertaken to build on data collection efforts and introducing cross-agency access to eLifespan Respite. Presenter will share how our commitment to providing statewide, 24/7 access to respite resources via Nebraska Resource and Referral System (NRRS) is linked with eLifespan Respite.

Music to Their Ears: Creating a Statewide Voucher System

- *Linda J. Porter, Project Coordinator, Lifespan Respite Washington, Easter Seals Washington, Seattle, WA*

Washington State's Lifespan Respite Coalition has been in existence as a clearinghouse and advocacy organization regarding respite since 2002. Meanwhile, respite options remained limited. Find out how a respite voucher system was created from the ground up while connecting unpaid family caregivers to existing respite resources already in compliance with the state's robust caregiver training requirements.



D-5 America the Beautiful: Respite Care for Our Nation's Heroes

Track: Family Caregivers

Room: Parthenon E

- *Jed Johnson, Director, National Veteran Caregiver Training Program, Easter Seals, Washington, DC*
- *Jennifer Dexter, Assistant Vice President, Government Affairs, Easter Seals, Washington, DC*

Respite providers are increasingly being called upon to provide support to Service Members/Veterans and their families. This crosses the lifespan, including:

- An older veteran experiencing memory loss due to Alzheimer's disease
- Active duty service members who have a child with autism or other special needs
- A parent caring for their son/daughter, a post-9/11 wounded warrior

This session will highlight useful training materials and discuss successful boots on the ground respite programs supporting our nation's heroes and their families. Presenters will also provide an overview of the current military/veteran respite care public policy landscape.



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Please visit our exhibit tables from 8:00am to 5:00pm outside the Parthenon Ballroom.



Thursday, October 9 – Conference, Day Two (cont.)

12:30pm – 1:00pm LUNCH BUFFET _____ Parthenon Ballroom

1:00pm – 2:15pm Community Innovations Plenary Session _____ Parthenon Ballroom

Respite from a New Perspective: Meeting Needs Without Missing a Beat

- *Moderator: Carol Westlake, Executive Director, Tennessee Disability Coalition*
- *Edgar Cahn, Founder and Chair, TimeBanks USA, Washington, DC*
- *Louise Barnes, Ph.D., Children and Youth Programs, Tennessee Department of Mental Health and Substance Abuse Services, Nashville, TN*
- *Laura Doutre, MPS, Assistant Commissioner, Policy and Innovation, Tennessee Department of Intellectual and Developmental Disabilities, Nashville, TN*

While the benefits of respite are well known, close to 90% of all family caregivers are still not using respite. This session will explore three very different, but compelling strategies for supporting families and making respite more acceptable, accessible and responsive to family needs, especially for underserved populations.

2:15pm – 2:45pm BREAK

2:45pm – 4:00pm **WORKSHOPS – Session E**



E-1 Respite Agency Best Business Practices – Instrumental to Your Success, in Harmony with Your Clients

Track: Business Development
Room: Acorn A

- *Doug Bergman, President and CEO, United Cerebral Palsy of Sacramento and Northern California, Sacramento, CA*

This session will provide an in-depth look at mission-critical business practices from UCP Sacramento/ Northern California. Doug Bergman, CEO of UCP Sacramento, will provide Respite Agency Leadership with an inside view of his journey that successfully doubled agency revenue, decreased bad debt and increased both client retention and satisfaction levels. Tune in to this informative seminar and learn how modernizing processes and following best practices will create operational harmony and the opportunity to expand your organization.



E-2 Successfully Implementing a Volunteer System to Increase Statewide Access to Respite Care

Tracks: Service Delivery Options and Lifespan Respite
Room: Acorn B

- *MaryJo Alimena Caruso, M.Ed, Coordinator, CareBreak at the Watson Institute and Master Trainer, TakeFIVE, Sewickley, PA*
- *Elizabeth Harris, M.S.W., Respite Project Coordinator/Volunteer Coordinator, Arizona Caregiver Coalition, Phoenix, AZ*
- *Mary Jones-Furlow, M.Ed., Project Coordinator, Temple University and Trainer, TakeFIVE, Philadelphia, PA*

Pennsylvania and Arizona have created two unique approaches to increasing the availability of and connecting family caregivers to volunteer respite providers. PA's TakeFIVE is an evidence-based statewide initiative to increase the number of trained volunteers in faith and community groups



Thursday, October 9 – Conference, Day Two (cont.)

through intensive training, technical assistance, resources and funding. Arizona's Caregiver Resource line is a successful component of their Lifespan Respite Program that operates by utilizing trained volunteers who link family caregivers with respite resources.



E-3 With a Little Help from My Friends: Technology and Hands-on Assistance Support Family Caregivers across the Lifespan

Tracks: Service Delivery Options and Lifespan Respite

Room: Acorn C

- *Elenore Parker, President, Rewarding Work Resources, Brookline, MA*
- *Jeffrey A. Keilson, Co-Founder, Rewarding Work Resources, Brookline, MA*
- *Amy Korstvedt Nazaire, Project Director, Massachusetts Lifespan Respite Project and Regional Director of Family Support and Children's Services, Massachusetts Department of Developmental Services, Northeast Region, Hathorne, MA*
- *David Besst, Caregiver Programs Specialist, Arizona Department of Economic Security, Division of Aging and Adult Services, Phoenix, AZ*

Presenters will demonstrate how technology, combined with hands on support for caregivers, can greatly enhance the ability of caregivers to find qualified respite workers who suit their needs. Despite projections of future shortages of respite and direct care workers, the presentation will show how a coalition of diverse organizations from two states, Massachusetts and Arizona, adapt and use a web-based, interactive registry of direct care workers to help family caregivers find experienced respite providers. In addition to using innovative technology, this initiative will show how coalitions can provide customer support for families, helping them identify workers, match worker skills with family needs, and vet workers. Participants will learn about concrete practices that they can bring back to their respective states and programs.



E-4 Caregiving through the Eyes of Hispanic Caregivers

Track: Family Caregivers

Room: Parthenon D

- *Lyda C. Arévalo-Flechas, PhD, MSN, RN, St. David's School of Nursing, Texas State University, Round Rock, TX*

The Hispanic population is rapidly growing and will soon be the largest racial/ethnic group among individuals age 65+. The majority of Hispanic older adults are cared for by their family. In order to support these caregivers, it is important to understand how they perceive their role and the values they assign to caregiving. The presenter will discuss core cultural values and linguistic issues affecting the manner in which Hispanics and their families approach caregiving.



Thursday, October 9 – Conference, Day Two (cont.)



E-5 Sustaining the Respite Coalition When Leadership Changes

Tracks: Advocacy and Networking and Lifespan Respite

Room: Parthenon E

- *Dawn Oakey Gartman, Senior Aging Program Specialist, Centralina Area Agency on Aging, Charlotte, NC*

What happens when your coalition experiences a change of leadership? How do you engage your board and membership? What do members want from the coalition? This presentation will highlight the experiences of the North Carolina Respite Care Coalition as it transitions through leadership change and the development of a sustainability plan.



E-6 Partnership between an Area Agency on Aging (AAA), an Aging and Disability Resource Center (ADRC), and the local Veterans Health Administration (VA) to Provide Lifespan Respite

Tracks: Service Delivery Options and Lifespan Respite

Room: Parthenon A, B, C

- *Susan D. Blevins, Care Transitions Intervention Coach, Care Coordination and VD-HCBS, Bexar Area Agency on Aging, San Antonio, TX*
- *Stella C. Newberger, Contract Adult Day Health Care and Respite Care Social Worker, Veteran-Directed Home and Community Based Services (VD-HCBS) Program Coordinator, South Texas Veterans Health Care System, San Antonio, TX*

Area Agencies on Aging and Aging and Disability Resource Centers get countless calls every day from veterans and their family members about a myriad of services, including the need for respite for the veteran, the veteran's spouse, and the veteran's minor dependents. This presentation will address how the AAA and the ADRC interface successfully with the VA health care systems to provide respite care services and caregiver education to veterans and their family members.

4:00pm – 4:30pm Closing Ceremony and Door Prizes _____ Parthenon Ballroom

5:00pm – 6:00pm Reception for Lifespan Respite Grantees and Partners _____ Crescent Room

Friday, October 10, 2014 - Lifespan Respite Learning Symposium

(By invitation only for Lifespan Respite Grantees and Partners. Separate Registration Required)

7:30am – 8:30am Registration and Breakfast

8:30am – 3:00pm Presentations and Interactive Discussion _____ Crescent Room





Mission

The Tennessee Respite Coalition's mission is to enhance the quality of life for family caregivers through respite.

Purpose

The Tennessee Respite Coalition provides relief to families and caregivers from the extraordinary and intensive demands of providing ongoing care.

History

In 1996, a small group of individuals interested in respite met to discuss the status of respite in Tennessee. They called themselves the Tennessee Respite Coalition and set goals of raising respite awareness and increasing respite services in Tennessee. This group received funding to further their efforts, which included developing a universal access point for respite and organizing Respite Awareness Days at the state Capitol. By 2000, the work had expanded to create a need for a full-time coordinator. At this time, the organization operated from the Tennessee Department of Mental Health and Substance Abuse Services. As the organization evolved, the TRC transformed into an independent 501(c)3 nonprofit in 2003, which allowed it to receive grants and donations to support respite services. In 2006, Congress passed the Lifespan Respite Act. Three years later, Tennessee was one of the first twelve states to receive a three-year Lifespan Respite grant. Through its work, the TRC has gained national presence and developed connections with respite leaders across the country. Today, the TRC receives support from eight different funding sources: Tennessee Department of Mental Health and Substance Abuse Services, Tennessee Commission on Aging and Disability, Corporation for National and Community Service, Baptist Healing Trust, West End Home Foundation, Peterson Foundation for Parkinson's, Community Foundation of Middle Tennessee and Caregiver Relief Program of Bedford County.

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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**, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the **Lifespan Respite Technical Assistance Center** which is funded by the Administration for Community Living, Administration on Aging (AoA) in the US Department of Health and Human Services.

ARCH was established with funding from the US Children's Bureau in 1990. The first respite conference was sponsored by the Children's Bureau with ARCH's assistance in the fall of 1991 in Washington, DC. In 1998, ARCH became the main sponsor of the annual national respite conference with state respite coalition collaboration. In 2004, ARCH turned to affiliated state respite coalitions to take the lead on hosting the annual conference, making it a true National Respite Network annual event supported by its grassroots membership.

ARCH, which stands for *Access to Respite Care and Help*, is a project of the Chapel Hill Training Outreach Project, Inc., Chapel Hill, North Carolina.

ARCH Advisory Committee for the Lifespan Respite Technical Assistance Center

State Representatives

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United Cerebral Palsy of Huntsville
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Linda J. Porter
Easter Seals Washington
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ARCH National Respite Network

Maggie Edgar
Seattle, WA

Jill Kagan
Annandale, VA

Bios of Plenary Session Panel Members

Louise Barnes, PhD, is a Developmental Psychologist, from Nashville, Tennessee who works with Respite programs and Early Childhood Prevention and Early Intervention programs funded by the Tennessee Dept. of Mental Health and Substance Abuse Services. She oversees implementation of the early childhood programs across the state. She has worked to develop respite services for families of children with Serious Emotional Disturbance since 1988. She, along with colleagues, was instrumental in helping to develop the Tennessee Respite Coalition in 1999 through a federal grant, and she continues to serve the TRC, now a non-profit agency, in an advisory capacity. She, together with colleagues, developed a model of Planned Respite services for families of children with Serious Emotional Disturbance.

Edgar Cahn is the founder of TimeBanking, a currency that rewards decency, caring and social justice in use in 40 states and 34 counties; and the Racial Justice Initiative (using a novel legal theory to dismantle structural racism in juvenile justice and child welfare). He is also the co-founder of the National Legal Services Program in the War on Poverty; the Antioch School of Law; the Time Dollar Youth Court of Washington DC; and the National Homecomers' Academy (enabling those returning home from prison to define themselves as community builders). Dr. Cahn formerly served as speech writer and Special Counsel to Attorney General Robert Kennedy and was the Executive Assistant to Sargent Shriver, Director of the Office of Economic Opportunity.

Laura Doutre, MPS, is the Assistant Commissioner of Policy and Innovation for the Department of Intellectual

and Developmental Disabilities. She is a member of the TN State Team, representing one of six states in the National Supporting Families Community of Practice, a Project of National Significance funded by the US Administration on Intellectual and Developmental Disabilities. Laura began working in the field of intellectual disabilities with a provider organization in 1992 and has spent her career devoted to serving people with intellectual disabilities.

Sharon Johnson is the Program Coordinator for Nebraska's Lifespan Respite Program at the Nebraska Department of Health and Human Services. In this role, she is responsible for coordinating the statewide Network through subgrants and contracts with local organizations and the University of Nebraska who carry out the activities that meet the unique respite care needs of the communities in which they operate. Nebraska places a great emphasis on a coordinated approach for ensuring statewide access across disability populations. Sharon is also directly involved in the Lifespan Respite Subsidy Program and the Disabled Persons and Family Support Program.

Greg Link is an Aging Services Program Specialist/Team Lead in the Office of Supportive and Caregiver Services with the Administration for Community Living (ACL)/U.S. Administration on Aging (AoA). He is the Federal program officer for the National Family Caregiver Support Program and the Lifespan Respite Care Program. He provides general oversight and technical assistance to the aging network on matters pertaining to the implementation of those programs as well as family caregiver support programs and

policies, the Older Americans Act and other aging and long-term services and support issues and is the programmatic lead on LGBT issues. Before coming to AoA, Greg worked at the National Association of State Units on Aging where he provided technical assistance and training to states on family caregiving, consumer direction and transportation. Greg has also worked at the community level as a case manager and social services manager at Senior Friendship Centers in Fort Myers, FL. There, he oversaw the social services staff and the delivery of services funded by the Older Americans Act, state funds and Medicaid waivers.

Tabitha Satterfield is an Aging Program Coordinator with the Tennessee Commission on Aging and Disability and has served in this capacity for the past 11 years. She coordinates the National Family Caregiver Support Program and the OPTIONS for Community Living Program in Tennessee. Tabitha has been the Project Director for two grants including the Alzheimer's Innovation Grant and currently the Lifespan Respite Grant.

Peggy Spaulding has worked as a Program Specialist for the Colorado State Unit on Aging for 8 years and specializes in contracts and the implementation and oversight of grants. She works with individuals of all ages through the Area Agencies on Aging (AAA), the Aging and Disability Resources for Colorado (ADRC), the Lifespan Respite Services and Dementia Capable, Sustainable Service Systems. Previously, she was the Executive Director at the Brain Injury Association of Colorado. Peggy has more than 20 years working with policy implementation and consumers with long term service and support needs.



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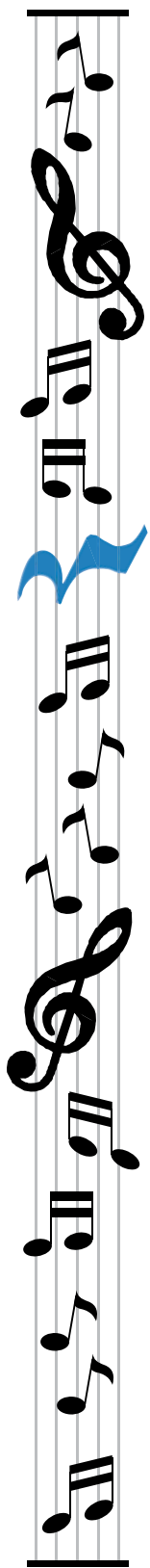
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