

2013 National Lifespan Respite Conference
 October 15-18, 2013
 Conference Program At-a-Glance
 (some changes may occur due to federal government closure)

THE FREEDOM
 TRAIL
 TO RESPITE



15th National Lifespan Respite Conference

October 15 to 17, 2013 ~ Boston

Tuesday Evening, October 15

3:00-7:30pm Registration

6:00-9:00pm Ice Breaker Reception and Welcome Program

Wednesday Morning, October 16

7:30am-5:00pm Registration and Help Desk

7:30-9:00 Breakfast Buffet

9:00-9:15 Opening Ceremony

9:15-10:00 Welcome to Boston

Rosalie Edes, Assistant Secretary

Massachusetts Executive Office of Health & Human Services

Ann Hartstein, Secretary

Massachusetts Executive Office of Elder Affairs

Elin Howe, Commissioner

Massachusetts Department of Developmental Services

10:00-10:30 Keynote Speaker



Sharon Lewis, Commissioner, Administration on Intellectual & Developmental Disabilities, and Acting Principal Deputy Administrator, Administration for Community Living, U.S. Department of Health and Human Services

In her dual roles, Commissioner Lewis is an important spokesperson for

individuals with intellectual and developmental disabilities in federal policy. From March 2010 to April 2012, Ms. Lewis served as the Commissioner of the Administration on Developmental Disabilities. Prior to her appointment as Commissioner, she served as the Senior Disability Policy Advisor to U.S. House Committee on Education & Labor, advising members of the Committee on legislative strategy and disability-related policy issues in education, employment and healthcare, and as a Kennedy Public Policy Fellow for U.S. Senate Subcommittee on Children & Families. Sharon 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.

10:30–11:00 Break

11:00–12:15 Workshops - Session 1

[A Trail to Respite, Support, Education: Creating Congregational Lifelines for Caregivers](#)

[Veterans Respite for Heroes at Home](#)

[Anchoring and Expanding a Service Delivery System for Families and their Members with Disabilities through Respite Care Programs](#)

[Giving Your Communities the Freedom to Care: How a Little Money can go a Long Way](#)

[The Freedom Trail to Respite: Your Roadmap to Caregiving without Regret](#)

[Does the Crisis Nursery Model really work? University-Led External Evaluation: Findings on the Enduring Impact of Crisis Nursery Services on Child/Family and Foster Care Involvement](#)

[What Happened to You? Integrating Trauma-Informed Care into the Crisis Nursery Setting](#)

[Overnight & Weekend Respite- Critical to a Family's Survival](#)

Wednesday Afternoon, October 16

12:30-1:15 pm Luncheon Buffet

1:15–2:00 pm Luncheon Speaker

Jonathan Evison, New York Times Best Selling Author
Most recent novel -- "The Revised Fundamentals of Caregiving"

Jonathan Evison is the author of three award winning novels: *The Revised Fundamentals of Caregiving*, *All About Lulu*, and The New York Times bestselling *West of Here*. He has written for National Public Radio, The New York Times, The Wall Street Journal, and Salon. Critics have compared Evison to Charles Dickens, J.D. Salinger, and Thomas Pynchon, Sherman Alexie has called Evison "the most honest white man alive." In his teens, Evison was the frontman and founder of the Seattle punk band March of Crimes, which featured future members of Soundgarden and Pearl Jam. He lives on an island in Washington.



2:00-2:30 Break

2:30-3:45 Workshops - Session 2

Got Respite? Ask-Plan-Do

Lifespan State Plan for Respite - Partners: Mapping South Carolina's Freedom Trail to Respite

Evaluation Outcomes and Evaluation of Respite Programs through the Lens of Social Role Valorization (SRV): A Brief Introduction to SRV and its Impact on Meaningful Program Design and Evaluation

Veterans Veteran Directed Respite: Using Participant-Direction to Support Veterans and Their Caregivers

The Elder Care Cliff: Challenging Caregivers to Survive and Thrive Beyond the A.E.D. (adaptation, exhaustion, damage & irrecoverable) Phases of Caregiving

Linking Families with Respite Providers: The Potential of Matching Service Registries

3:45-4:00 Break

4:00-5:15 Workshops - Session 3

A Revolution in Nebraska's Respite System- A Look Back and a Journey Forward

Collaborative Respite Care: A Team Approach for Children and Adults in Families Coping with Serious Illness

Ring-a-ling: Building a Statewide Resource Line to Support Family Caregivers

Respite for Caregivers of Children with Behavioral Health Needs

Leveraging Community Communications for Sustainable Respite and Caregiver Support

Making the Link: Connecting Caregivers with Community Resources

Evaluation Community Connections - The Impact is Evident

Enhanced Respite for Children with Autism and Behavioral Challenges - Program Development Considerations with Family-Centered Strategies

Wednesday Evening, October 16

Dinner on Your Own in Scenic Boston

Thursday Morning, October 17

7:30-5:00pm Registration and Help Desk

7:30-9:00 am Breakfast Buffet

9:00-9:30 am Keynote Speaker



Richard C. Antonelli, MD, MS
Medical Director of Integrated Care
and Physician Relations and Outreach
Boston Children's Hospital
Boston, MA

Dr. Antonelli is on the faculty of Harvard Medical School in the Department of Pediatrics. He is nationally known as a member of the Project Advisory Committee of the National Center for Medical Home Implementation at the American Academy of Pediatrics. He served on the Steering Committee for Care Coordination at the National Quality Forum. Since care coordination is so central to the effective transformation of the American health care system, Dr. Antonelli's work has been used for both adult and pediatric health care delivery systems.

Rich has personal experience with respite care, both in terms of seeking and providing it to friends and for family members. His own experience with his Mother's care served as the basis for a narrative published in the book, "Privileged Presence: Personal Stories of Connections in Health Care".

9:30-10:30 Lifespan Respite Plenary Session

"Sustaining Lifespan Respite Programs: Successful Strategies in Economically Challenging Times"

Moderator: **Jill Kagan**, Program Director, ARCH National Respite Network and Resource Center

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

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

Joyce Pohlman, Grants Coordinator, Access & Intake Division, Texas Department of Aging and Disability Services; and

Ellen Nau, Human Services Program Coordinator, Virginia Department for Aging and Rehabilitative Services, Division for the Aging

10:30-10:45 Break

10:45-12:00 Workshops - Session 4

[Respite Registries: Connecting Families with the Respite Workers they Need. From East to West, Two states share their experiences](#)

[Respite Now: Self-Care for Caregivers](#)

[On the Trail in Florida: One State's Approach to Family Caregiver Supports](#)

[Prepare to Care: Training Resources and Support Options for Informal and Formal Caregivers](#)

[Emergency Respite as a Service Delivery Option: The Illinois Respite Coalition Model for Illinois](#)

[Lifespan Respite for All Ages: Priorities for Improving Respite Services in OH](#)

Thursday Afternoon, October 17

12:30-1:15 pm Lunch

1:15-2:30 Respite Research Plenary Panel

Moderator: **Emily Kearns, PhD**, President of Kearns Consulting

Judith G. Gonyea, PhD, Professor and Chair, Social Research Department,

School of Social Work, Boston University

Joan Hyde, PhD, CEO, Co-President Massachusetts Gerontology Association,
Ivy Hall Senior Living and UMass Boston Gerontology Institute

Additional panelist to be announced

2:30-3:00 Break

3:00-4:15 Workshops - Session 5

Coaching Family Caregivers Along the Freedom Trail to Respite

Development and Implementation of a Coalition Strategic Plan

Exploring the Experiences of Family Caregivers in Cape Cod

Freedom from Abuse: Addressing Risk & Response in Respite

Volunteer Experienced Respite Volunteers: Using Senior Companion
Volunteers for Respite

Caregiver Characteristics Associated with use of Respite Care: Results from a
Texas 2012 Statewide Survey

New! Providing Respite to US ARMY Families

4:30-5:00 Raffles and Closing Ceremony

Some surprises in store! Join us for the Closing Ceremony on Thursday, October 17 at 4:30pm in the Georgian Room! Fabulous raffle prizes include a Gift Certificate for a 2 night stay at the Regent Palms Turks and Caicos, an iPad and more! You must be present to win!

Friday, October 18

Lifespan Respite Grantee and Partner Learning Symposium

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

8:30-3:00 pm – Presentations and interactive discussions

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

October 5, 2013