National Corporate Sponsors
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- ARCH National Respite Network
- Respite Services Association, Inc. (dba California Respite Association)
- Imperial Valley Respite, Inc.
- Inland Respite, Inc.
- Valerie and Jacob Langeloth Foundation (Lifespan Respite Care Summit)
- Sonia Corina dba Bay Respite Care (Awards Dinner)

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Route 66: The Respite Highway that’s the Best!
Burbank, CA

National Conference Planning Committee, Other Conference Volunteers and Exhibitors

National Conference Planning Committee Members

Pre-Conference Promotion, Registration, Decorations, Sponsorship/Grants Procurement
Ray Alcantra, David Bernstein, Annie Clark, Doug Cunningham, Sharon Francis, Lynnette Grigone, Mike Huckins, Jill Kagan, Daniel Kutner, Stacey Martinez, Edisson Mas, Randy McGlauthing, Mike Mathers, LaTeasha Murphy, Beatriz Rodriguez, Dianne Rose, Jamie Salas, Diane Toevs, Sarah Wiggins, Susan M. R. Wiggins, Tom Wiggins

Registration/Breakout Session Room Hosts/Round Table Facilitators
Louise Barnes, Debbie and Nicholas Bowers, Jolene Canales, Stacey Cranfill, Bonnie Danowski, Rachel Ford, Sharon Francis, Kelsey Holt, Mike Huckins, Ann Lawrence, Stacey Martinez, Lee Ann Massey, Lea Montgomery, Kerstin McFarlane, Lindsay Peterson, Joe Scott, Edgar Vasquez, Susan M. R. Wiggins

Awards Dinner Committee

Award Presenters
MaryJo Alimena-Caruso, David Besst, Sherri Blome, Debbie Bowers, Janelle Clifton, Janis De Baca, Ohio State Representative Matthew J. Dolan, Maggie Edgar, Kelly Evans, Natalie Leek-Nelson, Lindsay Peterson, Dianne Rose, Valerie Saiz, Patricia Schindler and Jennifer Tschannen, David and Faye Wetherow, Susan M. R. Wiggins, Wendy Zwicker

Exhibitors
Accredited, ARCH National Respite Network, California Respite Association, Friends of Route 66, Imperial Valley Respite, Inland Respite Inc., Leeza’s Place, National Certified Insurance, Philadelphia Insurance Companies and National Multiple Sclerosis Society

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Breakout Session D: 1:30p-2:45p (Friday)

D-1: The Caregiver’s Journey: From Brokenness to Wholeness– Bonnie Danowski
This session will take participants through the grief process that all caregivers experience as their loved one is diagnosed and progresses through their disease/condition. It is called a journey because it has its ups and downs and caregivers can make choices as they travel the path.

D-2: Autism Respite Services and Older Adult Volunteers: Meeting 2 needs with 1 program– Patricia Wright
Learn how a volunteer program, which successfully trained older adult volunteers to work with autistic children, was funded and implemented. Topics include: Introduction to Autism, community, family, communication, community, family, behavior and socialization, curriculum funding and implementation.

D-3: Camp for Caring– Donna Schenapp
Learn about a model respite camp that takes care of clients/loved ones while the primary caregivers can take a break. The client/loved one, usually someone with Alzheimer’s or dementia, spends the weekend at a retreat center with 24 hour care and activities similar to Adult Day Care.

D-4: The Logic Model– Casandra Firman
A critical tool to help translate research and evaluation into outcome based quality services and future funding possibilities for the respite community.

Breakout Session E: 3:00p-4:15p (Friday)

Review data collection and assessment methods to identify program risk and opportunity and translate this information to implement critical changes for compliance, quality, and service expansion.

E-2: Take Time for Respite– Models and Support for Family Caregivers of Adults with Dementia– Donna Benton and Claudia Elano
Models of respite that support family caregivers serving adults with dementia including multi-cultural and comprehensive planning approaches with specific use of retreats, arts support and age and culturally appropriate programs.

E-3: Overcoming Challenges for Respite Agencies working with the Spanish-Speaking Population– Edgar Vasquez AND Claudia Elano
A) How respite agencies can successfully implement strategies and share resources to serve the Spanish-speaking population AND B) This Rotary International sponsored exchange will focus on family caregiving and respite in Argentina.

An overview of different CPR/FA programs so respite agencies/parents can choose what is appropriate for their respite workers and how this training benefits their clients/children AND B) Will Emergency Personnel know how to effectively respond to persons with special needs? A sample Personal Emergency Plan will help caregivers and respite agencies prepare First Responders.

Roundtable Topics (RT's)...

THURSDAY, SEPTEMBER 24

During Breakout Session A
1. Lifespan Respite Web and Database Prototype
2. Update on Autism
3. Staying connected to your vision and mission
4. Universal Criteria for Respite Eligibility

During Breakout Session B
5. Fantasy Respite Booking
6. Estate Planning
7. Training Best Practices
8. Next Steps Coalition Building
9. Readiness for New Technologies
10. Willingness to Improve Programs
11. Durable Power of Attorney
12. Faith Based Programming
13. Meaningful Family Intake Process

FRIDAY, SEPTEMBER 25

During Breakout Session C
14. Relationship building: referrals & agencies
15. Fundraising Ideas
16. Management of Behaviors
17. In-Service Training with Today’s Technology

During Breakout Session D
18. Surviving State Cutbacks
19. Grab Bag of Fun Respite Activities
20. Co-payment and/or Fees for Respite Service?
21. Communication Tools for Non-Verbal People

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Being Sandwiched: Working Adults Caring for Children and Aging Family Members

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Educational Objectives
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Training Schedule
Thursday, September 24th
Friday, September 25th

Thank You Committee Members

Thank You Sponsors
Keynote Speakers

Status of the Lifespan Respite Program Implementation and other AoA Initiatives
Assistant Secretary Kathy Greenlee
Administration on Aging,
US Department of Health and Human Services
Royal Crest Ballroom
Thursday, September 24, 2009, 9am-10:15am

On June 25, 2009, the United States Senate unanimously confirmed Kathy J. Greenlee as the U.S. Assistant Secretary for Aging. She brings a wealth of experience on aging issues to national prominence with her previous experience as the Kansas Secretary on Aging where she oversaw a range of programs for older adults including the Older Americans Act, Medicaid long-term care and regulation of nursing homes. In her new role at the helm of AoA, she has already declared that support for family caregivers will be one of her highest priorities. This comes at a time when AoA and the national aging network is undergoing significant change and assuming a greater leadership role in bridging the gaps in home and community based services across the aging and disability spectrum. As AoA begins implementation of the Lifespan Respite Care Act this year, Assistant Secretary Greenlee will share her exciting visions for this effort as well as AoA’s work to support family caregivers under the National Family Caregiver Support Program and the most recent AoA innovations currently underway to address the needs of family caregivers.

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The Conference Highlights

In More Detail...

Breakout Session A: 1:30p-2:45p (Thursday)
A-1: 14,000 Islands: Navigating the Boundary with Community- David and Faye Wetherow
Learn a new pattern for exploring, ‘mining’ and mobilizing the field of relationships, shared interests and welcoming places that seem to be hidden but are actually just a step or two away. This is a practice workshop– you’ll begin to create a personal navigation map and plan your next steps.
A-2: Respite by Numbers: Using respite outcomes to develop and retain funding– Whitney Fuchs
All too often taking a break is one of the first things cut in a family budget. While respite providers understand all too well the danger of losing the perspective gained by taking a break, building that understanding with funders is crucial to program sustainability.
A-3: Grief, Belief, and Open Wheel Race Car: Younger Generations Recruitment and Retention– Kori Novak
How to recruit and retain younger individuals into the profession and in volunteer organizations by making them part of the “crew”. Attendees will have the opportunity to share best practices.
Opening Doors Project Adventure is a research project designed to promote inclusive recreational activity for special needs children by pairing them with a trained “mentor “coach”. Parents can simultaneously exercise themselves or have some personal downtime.

Breakout Session B: 3:00p-4:15p (Thursday)
B-1: Crises Averted– Crisis Nursery Model and Family Outcomes– Natalie Leek-Nelson
An overview of the crisis nursery model as an alternative to foster care with a focus on services and delivery methods as well as an assessment of long term data to support program effectiveness and secure funding.
B-2: Reasons, Respect, and Relationships– a workshop for caregivers and respite providers!- Louise A. Bruce
“Reasons” for having respite and ways to ensure mutual “respect” needed in the family/client and respite provider relationship. We will cover respect for the family, breaking down of fears, “Treasure Hunting” tools to find each person’s gifts amidst their limitations and subjects like interview verbiage and sensitivities.
B-3: Cancelled
B-4: Advocacy Odyssey– Senator Byars, Bonnie Danowski, and Jill Kagan
Explore the roads to creating an enjoyable and effective advocacy program for your organization and coalition.

Breakout Session C: 10:30a-12:00p (Friday)
C-1: Get a Life! Creating respite that benefits the individual and the family through socially valued roles– MaryJo Alimena Caruso and Gay Caruso
Social Role Valorization: this presentation will explore respite service models and examine whether the potential for valued roles is facilitated or impeded by the provision of respite care.
C-2: The Role of Care Notebooks in the Respite Center– Jay Liebeskind
A care notebook is used to organize medical records, appointments, educational records, tax documentation and more. “Directions” book will be provided.
C-3: Preventative respite care through proactive social work and health education interventions with persons with dementia– Troy Andersen
Based on the Center of Alzheimer’s program, care providers are provided dementia education and are strongly encouraged to seek respite opportunities early in the disease process.
C-4: A Six-Year Journey to Viability– Dr. Barbara Snyder
Over a 6 year period, a coalition of consumers, service providers and advocates conducted surveys of caregivers and providers to identify respite needs, developed an operations plan to address the needs, and garnered funding from state agencies and private foundations.

Conference Schedule

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The 2009 National Respite Conference will attract respite professionals, respite providers, advocates, families and consumers from around the United States. Route 66 and our nation’s highways keep individual states connected and therefore united as one nation; it inspires us to collaborate so our vision of lifespan respite remains strong. This year’s Route 66 topic themes include:

- **Road Readiness** (Service Diagnostics; Technology Tune ups)
- **Where the Rubber Hits the Road** (Research, Fundraising, Sustainability)
- **Respite Roadmaps** (Advocacy, Coalition Building, Lifespan Summits)
- **Roadside Picnics** (Best Practices Round Table Discussions with Facilitators)
- **Scenic Vistas Along the Way** (Innovative Services and Updates from Sponsoring States)

Travel out west to enjoy the best of what our nation has to offer related to respite! For example, what is the latest in research and what’s going on with the Federal Lifespan Respite Care Act? Discuss best practices by specific topics at individual round tables assisted by a facilitator. Enjoy an academy awards style respite awards dinner as this year’s Welcome Party!

The National Respite Conference Planning Committee’s selection process will focus on interactive presentations while discussing innovative respite services, relevant research, technology or policy and coalition building issues. Presenters will be selected to ensure that issues across the lifespan will be addressed, as well as issues that relate to implementation and funding of the new Lifespan Respite Care Program. Issues that address the continuum of respite service delivery from planned to emergency services will also be a priority.

Dr. Hilary Arksey, Ph.D., Professor
Social Policy Research Unit
University of York, England

Casandra Firman, Training and Technical Assistance Coordinator
FRIENDS National Resource Center for Community Based Child Abuse Prevention

Dale Lund, Ph.D. Professor & Chair
Department of Sociology
University of California, San Bernardino

Royal Crest Ballroom
Thursday, September 24, 2009, 10:45a-12:00p

Casandra Firman and Dr. Dale Lund will provide an overview of current respite research findings, describe federal expectations for program evaluation, relate the importance of research and evaluation to public and private funding opportunities, and discuss recommendations for future respite research and the role each of us must play in the research arena. They will attempt to answer the following questions:

- What are federal expectations for evidence based programs now and on the horizon?
- How effective are respite services for family caregivers? Is respite accomplishing what we expect it to?
- What are the commonly used measures to know if respite is helpful to family caregivers?
- How can we make respite more effective for family caregivers?
- How important are respite services for family caregivers?
- Why do we need to make sure that we improve respite services and document the ways in which it is helpful?

Dr. Arksey will look at what is known about respite effectiveness. This will include mapping out the nature of the evidence base; presenting key findings about the impact and outcomes of respite; and considering methodological weaknesses in evaluations of respite interventions. Dr. Arksey will conclude by explaining why more rigorous and thoughtful research is essential in today’s economic climate.

Dale Lund, PhD, joined the faculty at California State University San Bernardino in January, 2009, as a professor and Department Chair of Sociology after having been on the faculty at the University of Utah Gerontology Center for 28 years. He has conducted funded research (Administration on Aging, National Center for Nursing Research, national Alzheimer’s Association) and published numerous journal articles on family caregiving and use of respite services for the past 26 years. He previously served as the President of the Utah Chapter of the Alzheimer’s Association. His current research is focused on testing interventions to improve the effectiveness of respite services for family caregivers.

Casandra Firman, Evaluation Consultant, has worked as an Evaluation Specialist and Technical Assistance Coordinator for the ARCH and FRIENDS National Resource Centers. She has produced many written materials including Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers, the results of respite and crisis care respite evaluations conducted in collaboration with the University of North Carolina and others, and has presented workshops on the topic at state, national and international conferences.

Dr. Hilary Arksey is Senior Research Fellow in the Social Policy Research Unit at the University of York, England. Her research interests focus on community care, and in particular family caregivers. Recently, Dr. Arksey completed projects include evaluations and literature reviews of respite care services. During summer 2008, Hilary acted as Special Adviser to the British Government’s Work and Pensions Select Committee inquiry looking at support for caregivers.
Keynote Speakers

En Route to a Respite Environment Rich in Relationships
David and Faye Wetherow
Community Works
Royal Crest Ballroom
Thursday, September 24, 2009, 12:30pm-1:15pm

If we focus on the “intersection” of people’s interests, connections and capacities, we find ourselves in an environment that is rich in relationships. If we think about respite as opportunity to move in the direction of connections, companionship and contribution, we can tap into that rich environment.

David and Faye are parents and caregivers. They have both had a long history of developing innovative services (Cooperatives and Microboards), training facilitators, evaluating services, building value-based systems of accountability and management, and helping the States build delivery systems that are person-centered, family-friendly and strongly community-based.

Map from the Holiday Inn to the Pickwick Gardens
Directions from the Holiday Inn to Pickwick Gardens
1. Start going SOUTHWEST on E ANGELENO AVE toward S 1ST ST. 0.1 mi
2. Turn RIGHT onto S 1ST ST. 0.1 mi
3. Turn LEFT onto S OLIVE AVE. 0.4 mi
4. Turn LEFT onto E VICTORY BLVD. 0.2 mi
5. Stay STRAIGHT to go onto S MAIN ST. 0.7 mi
6. Turn RIGHT onto W RIVERSIDE DR. 0.1 mi
7. 1591 W RIVERSIDE DR is on the RIGHT. 0.0 mi

Map of the Pickwick Gardens Conference Center

Things to Do While in the Los Angeles Area
- Organized Tours of the area: www.starlinetours.com
Complimentary Shuttle from the Burbank Airport to the Holiday Inn
This complimentary shuttle runs approximately every 15 minutes. It can be caught on the baggage claim level on the island (look for the hotel shuttle sign). A vehicle with an ADA lift and wheelchair tie-down should be arranged a day in advance by calling The Holiday Inn at 1-(818)-841-4770.

ADA Shuttle on Conference Days
The California Respite Association has contracted to have an ADA Shuttle on conference days to go between the Holiday Inn Burbank Media Center and the Pickwick Gardens Conference Center from 7:30am to 9:30am and 3:30pm and 5:30pm each conference day. The shuttle vehicle has a lift and two wheelchair tie-downs and can accommodate over twenty persons per shuttle run. If you need transport between 9:30am and 3:30pm, make a transportation request at the registration desk. The distance between the Holiday Inn and the Pickwick is approximately 1.7 miles.

Conference Satisfaction
It is our goal to assure that all registrants are satisfied with every aspect of the conference and to see that your staff is better than you anticipated. If you are not satisfied with an aspect of the conference, please stop at the registration booth and see if our volunteers can help meet your needs, help you get into another workshop or work to improve your conference experience. If you are not getting satisfactory results, please ask the registration volunteers to contact Mike Huckins.

Feedback on our educational offerings is always welcome. Please use the evaluation sheets inserted into this Conference Program and or ask for an evaluation form at the end of each session.

Room hosts, round table facilitators and persons helping out in registration are volunteers and we appreciate their support.

Certificates of Completion
For registered conference participants, the California Respite Association will provide certificates of completion that include conference hours and sessions for all conference attendees who request a certificate. Please sign in with your room host so that you can be recognized for your attendance. Certificates will generally be available at the conclusion of each session. Main ballroom sessions can be picked up at registration. Breakout session

Keynote Speakers

Putting You in the Driver’s Seat: National Respite Coalition Legislative News and Lifespan Respite Funding Update

Jill Kagan
Chair
ARCH National Respite Coalition

Greg Link, Aging Services Program Specialist, Office for Community-based Services, Administration on Aging

Royal Crest Ballroom
Thursday, September 24, 2009, 9-10:15am

Greg Link oversees the management of both the National Family Caregiver Support program and the newly funded Lifespan Respite Care program at AoA. He will provide an update on the status of Fiscal Year 2009 Lifespan Respite grantees, an overview of funded programs and expected outcomes during the three year grant period, and guidance and insights into future cycles of Lifespan Respite funding.

Jill Kagan will informally provide the latest news from Washington, DC on federal legislation and funding for respite and crisis care including:

- FY2010 Lifespan Respite Appropriations
- Health Care Reform and the expected impact on home and community-based services
- The Child Abuse Prevention and Treatment Act, including crisis nurseries
- Respite and Family Caregiving for Military Families and Veterans
- National Respite Coalition News and State Updates

Ms. Kagan is Chair of the National Respite Coalition, the policy division of the ARCH National Respite Network. Ms. Kagan has served in this capacity since 1994, promoting respite and crisis care in national and state policy and programs. Currently, she is the founder and facilitator of the Lifespan Respite Task Force, a coalition of national, state and local organizations which promotes lifespan respite in national policy. The Task Force, along with the NRC led the effort to enact the Lifespan Respite Care Act of 2006. Ms. Kagan will soon take on the additional role of Program Director for ARCH Lifespan Respite Resource Center activities.
Keynote Speakers

Being Sandwiched: Working Adults Caring for Children and Aging Family Members
Margaret B. Neal, Ph.D., Director
Institute on Aging
Portland State University
Royal Crest Ballroom
Friday, September 25, 2009, 12:30pm – 1:15pm

Dr. Margaret Neal will present the challenges and benefits related to working sandwich generation caregivers based on research funded by the Alfred P. Sloan Foundation. Findings to be discussed: the effects of multiple caregiving responsibilities on one’s work and home life, effective and non-effective coping strategies, and what changes can be made by employers, health and social service providers, and policy makers to help people who are engaged in paid work and unpaid family caregiving responsibilities.

Margaret B. Neal, Ph.D., is Director of the Institute on Aging and Professor of Community Health in the College of Urban and Public Affairs at Portland State University. She teaches graduate courses in gerontology and research methods and leads a service-learning program to Nicaragua. Her research has focused on the challenges and opportunities of managing both paid employment and informal care to elders and how the public and private sectors can facilitate work-family integration. She recently completed a book with colleague Dr. Leslie Hammer (Working Couples Caring for Children and Aging Parents, Lawrence Erlbaum, 2007), and she has written several other articles, book chapters, and books (e.g., Balancing Work and Caregiving for Children, Adults, and Elders, Sage, 1993; Work and Caring for the Elderly: International Perspectives, edited with Viola Lechner, Taylor & Francis, 1999) on this and related topics. Her other research and teaching interests include issues surrounding age-friendly cities, global aging, transportation options for older adults, older workers and retirement, and health promotion strategies.