The Many Faces of Respite

CONFERENCE PROGRAM

Learning and Sharing...Together!

Arizona Caregiver Coalition
www.azcaregiver.org

Collaboration
Advocacy
Resources
Education
www.archrespite.org

In partnership with the ARCH National Respite Network and the National Respite Coalition

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ARIZONA CAREGIVER COALITION

MISSION AND VISION

The mission of the Arizona Caregiver Coalition is to create awareness of caregiving issues and improve the quality of life for caregivers and care recipients through advocacy, information and education, support, and access to resources.

The vision of the Arizona Caregiver Coalition is for all Arizona caregivers to have knowledge of and access to resources that support them.

BENEFITS OF MEMBERSHIP

Membership in the Arizona Caregiver Coalition means having a powerful collective voice to advocate for family caregivers! It means meeting new people that support caregivers, learning new ways to reach and help caregivers, and creating a statewide network to allow caregivers easier access to critical support services like respite and training.

OBJECTIVES

The Arizona Caregiver Coalition, in conjunction with our community partners and members, will work together to achieve the following shared objectives:

- Promote awareness of caregiving and its challenges.
- Strengthen and unite existing resources and information supportive of caregivers and respite care.
- Advocate for caregivers and their families relative to supportive programming.
- Work to improve service delivery and reduce barriers to caregivers receiving supportive services.
- Facilitate the development of a system of easy access to respite care for caregivers.
- Respond to community needs and provide for needs of caregivers now and in the future.
- Improve public and private non-profit collaboration relative to caregiver support and respite care.
- Support strategies and activities related to family caregivers included in the State Plan on Aging.
- Recruit and supervise volunteers to staff a caregiver resource hotline.

www.azcaregiver.org
## Overall Schedule

### Tuesday, Nov 1st - Pre-Conference Intensive and National Conference Reception

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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:30am – 3:30pm</td>
<td>Registration</td>
<td>Media Center Lobby</td>
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<tr>
<td>9:30am – 10:00am</td>
<td>Continental Breakfast</td>
<td>Media Center East</td>
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<tr>
<td>10:00am – 3:30pm</td>
<td>Statewide Respite Summit</td>
<td>Media Center East</td>
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<tr>
<td>3:30pm – 5:00pm</td>
<td>Resource Fair and Vendor Display</td>
<td>Exhibitor Area</td>
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<tr>
<td>5:00pm – 7:00pm</td>
<td>Conference Networking Reception</td>
<td>Hotel Courtyard</td>
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### Wednesday, Nov 2nd - Conference, Day One

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<td>Continental Breakfast</td>
<td>Media Center East</td>
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<tr>
<td>8:30am – 9:00am</td>
<td>Conference Welcome</td>
<td>Media Center West</td>
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<tr>
<td>9:00am – 9:45am</td>
<td>Keynote - Edwin Walker</td>
<td>Media Center West</td>
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<tr>
<td>9:45am – 11:00am</td>
<td>Plenary Panel - New VA Programs</td>
<td>Media Center West</td>
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<tr>
<td>11:15am – 12:15pm</td>
<td>Plenary Panel - Lifespan Respite</td>
<td>Media Center West</td>
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<tr>
<td>12:15pm – 1:15pm</td>
<td>Lunch</td>
<td>Media Center East</td>
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<tr>
<td>1:30pm – 2:30pm</td>
<td>Cultural Diversity Plenary Session</td>
<td>Media Center West</td>
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<td>2:45pm – 3:45pm</td>
<td>Breakout Sessions</td>
<td>See Session Detail</td>
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<tr>
<td>4:00pm – 5:00pm</td>
<td>Breakout Sessions</td>
<td>See Session Detail</td>
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<tr>
<td>6:00pm – 8:00pm</td>
<td>Presenter’s Party/ Mexican Fiesta</td>
<td>FSL Caregiver House</td>
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### Thursday, Nov 3rd - Conference, Day Two

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<td>7:30am – 8:30am</td>
<td>Continental Breakfast</td>
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<tr>
<td>8:30am – 9:30am</td>
<td>Network Building Plenary Session</td>
<td>Media Center West</td>
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<td>9:45am – 10:45am</td>
<td>Breakout Sessions</td>
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<td>11:00am – 12:00pm</td>
<td>Breakout Sessions</td>
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<tr>
<td>12:15pm – 1:15pm</td>
<td>Lunch</td>
<td>Media Center East</td>
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<td>1:15pm – 2:30pm</td>
<td>Service Options Plenary Session</td>
<td>Media Center West</td>
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<tr>
<td>2:45pm – 3:45pm</td>
<td>Breakout Sessions</td>
<td>See Session Detail</td>
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<td>4:00pm – 5:00pm</td>
<td>Breakout Sessions</td>
<td>See Session Detail</td>
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<tr>
<td>7:00pm – 9:30pm</td>
<td>Phoenix Coyotes Hockey Game</td>
<td>Jobing.com Arena</td>
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### Friday, Nov 4th - Grantee Meeting

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<th>Time</th>
<th>Event</th>
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<tr>
<td>8:30am – 9:00am</td>
<td>Continental Breakfast</td>
<td>Solana B,C,D</td>
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<tr>
<td>9:00am – 3:00am</td>
<td>Grantee’s Meeting</td>
<td>Solana B,C,D</td>
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Tuesday, November 1st – Pre-Conference Intensive

Arizona Statewide Summit on Respite!
Media Center - West

8:30am - 3:30pm  REGISTRATION – Media Center Lobby

9:30am - 10:00am  CONTINENTAL BREAKFAST

10:00am - 10:15am  SALUTE TO SUMMIT ATTENDEES – FAMILY CAREGIVER MONTH!
Melanie Starns, MAG, Assistant Director, Arizona Department of Economic Security, Division of Aging and Adult Services

This address will kick-off the Summit with an overview of how the Department of Economic Security and its community partners are approaching support of caregivers, and the process of developing networks that provide streamlined access to services that are effective and consumer friendly.

10:15am - 10:45am  RESPITE . . . WHAT A RELIEF - FAMILY CAREGIVER STORIES
Panelists: Margaret “Margie” Preece, Greg Heard, Melissa Coats

Inspiration from family caregivers and the loved ones they are caring for as they describe how respite services have impacted their lives.

10:45am - 11:30am  PANEL DISCUSSION - SUPPORTING FAMILY CAREGIVERS
Moderated by Jim Murphy, President and CEO of Pima Council on Aging
Panel Members: Mary Beals Luedtka, NACOG; Elisa Davis, WACOG; and Scott Hawthornthwaite, Region One, Inc.

Learn about current efforts in Arizona to support family caregivers across the lifespan. Panel members will highlight innovative ways being used in Arizona to provide respite for caregivers needing to take a break.

11:30am - 11:50am  THE ARIZONA CAREGIVER COALITION - CONNECTING THE DOTS!
David Besst, Caregiver Support Specialist, Arizona Division of Aging and Adult Services (DAAS), and Co-Chair of the Arizona Caregiver Coalition

Find out how the coalition is working with DAAS and the Lifespan Respite Program, including the latest on the new Lifespan Respite Caregiver Resource Line and the new Caregiver Assessment Tool being used to authorize respite services.

11:50am – Noon  BREAK
Arizona Statewide Summit on Respite!
Media Center - West

**Tuesday, November 1st – Pre-Conference Intensive** (cont.)

**Noon - 1:00pm**  
**LUNCH/NETWORKING – MEDIA CENTER EAST**  
Including special presentation!

**1:00pm - 1:30pm**  
**KEYNOTE PRESENTATION**  
*Strong Coalitions Make Effective Lifespan Respite Systems*  
Jill Kagan,  
MPH, Program Director - ARCH National Respite Network & Resource Center

State Lifespan Respite Programs are designed to develop systems of community-based respite for family caregivers caring for anyone of any age with special needs. Learn how state respite coalitions around the country are collaborating with their state agency partners and others in building and sustaining State Lifespan Respite Systems that are making respite more accessible for all family caregivers.

Jill Kagan

**1:30pm - 1:40pm**  
**WHAT’S THE PLAN FOR ARIZONA?**  
Linda Martin, Vice President, Foundation for Senior Living

Setup for facilitated discussions related to the ACC’s CARE Committees

**1:40pm - 2:30pm**  
**BREAKOUT SESSIONS – CARE COMMITTEES**  
Facilitated by various volunteers

C – Collaboration

A – Advocacy

R – Resources

E – Education

**2:30pm - 2:40pm**  
**BREAK**

**2:40pm - 3:00pm**  
**REPORT OUT ON BREAKOUT SESSIONS**

**3:00pm - 3:15pm**  
**NEXT STEPS FOR ARIZONA**  
David Besst  
Overview of potential activities attendees can take with them as collectively we work to further implement lifespan respite into Arizona’s system of support for family caregivers.
Tuesday, November 1st – Pre-Conference Intensive  (cont.)

3:15pm - 3:30pm  INSPIRATIONAL CLOSING PRESENTATION
ACC BOARD MEMBER AND “CAREGIVER ADVOCATE”
Bonnie Danowski has been the primary caregiver for her husband of 47 years, Jim, diagnosed with MS 40 years ago. She also has a primary role with her son, who is bipolar. Having the experience of caregiving has given her a passion to do whatever is possible and sometimes impossible, to make the lives of caregivers easier, happier and healthier. As a leader in Valley Interfaith Project, she partnered in drafting the legislation that authorized the AZ Lifespan Respite Care Program.

3:30pm  RESPIRE SUMMIT ADJOURNED

3:30pm - 5:00pm  RESOURCE FAIR – VENDOR DISPLAYS

5:00pm - 7:00pm  CONFERENCE NETWORKING RECEPTION – Outside Patio
Hors D’oeuvres and Cash Bar

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When you need assistance

AZ Links is Arizona’s Aging and Disability Resource Center (ADRC), created to help Arizona Seniors, People with Disabilities, Caregivers and their Family Members locate resources and services that meet their needs.

Find information about:

- Support services
- Public programs
- Housing options
- In-home care

All at your fingertips –

www.AzLinks.gov
Day One - Wednesday, November 2nd

7:30am - 4:30pm  REGISTRATION – Media Center Lobby

7:30am - 8:30am  CONTINENTAL BREAKFAST - Media Center East

8:30am - 9:15am  WELCOME TO THE CONFERENCE!

There will be a brief opening ceremony, followed by a reading of the Governor’s Proclamation declaring November as Arizona Family Caregiver Month! We’ll also set the tone for the conference by attempting to set a world record for the loudest applause ever in appreciation of family caregivers! We’ll also provide general information about the hotel facilities, highlight entertainment opportunities, and encourage interaction with the resource tables in the exhibit area.

9:15am - 9:30am  KEYNOTE COMMENTS – HONORABLE EDWIN L. WALKER

As the Deputy Assistant Secretary for Program Operations with the Administration on Aging (AoA) within the U.S. Department of Health and Human Services, Edwin L. Walker serves as the chief career official for the federal agency responsible for advocating on behalf of older Americans. Learn the latest on home and community-based long-term care programs designed to afford older people and their caregivers the ability to age with dignity and independence, including information on the promotion and implementation of evidence-based prevention interventions proven effective in avoiding or delaying the onset of chronic disease and illness.

9:30am - 10:45am  PLENARY PANEL DISCUSSION – U.S. Department of Veterans Affairs

Through a panel presentation this session will provide an overview of VA services and supports for Veterans at home and their caregivers, which includes VA partnership with ADRCs, Veteran Directed Services, innovative programs including volunteer respite programs, as well as information on the new VA Caregiver Support Program and the Veteran-Community Partnership initiative.

Learn about the latest program initiatives being introduced by the VA to support family caregivers through respite services.

Panel Moderator: Daniel Schoeps, Director, Purchased Long-Term Care Group Geriatrics & Extended Care, U.S. Department of Veterans Affairs
Panel Guests: Sarah Hyduke, Project Lead Veteran-Community Part Laura Balun, Director, Voluntary Service Office Margaret Kabot, National Program Manager, Caregiver Support

11:00am - 12:15pm  PLENARY PANEL DISCUSSION - THE FEDERAL LIFESPAN RESPITE PROGRAM: BUILDING INNOVATION, COLLABORATION AND DIVERSITY IN SERVICE DELIVERY ACROSS THE LIFESPAN

Moderated by Greg Link, Aging Services Program Specialist, from AoA’s Office of Community-Based Services. Hear from three current state grantees, South Carolina, Oklahoma, and Massachusetts about the programs being developed through the Lifespan Respite grants they were awarded.
Day One - Wednesday, November 2nd (cont.)

12:15pm - 1:30pm  LUNCH / NETWORKING

1:30pm - 2:30pm  PLENARY PRESENTATION – CULTURAL DIVERSITY TRACK

    The Many Faces of Family Caregivers!

    **David W. Coon**, Ph.D., Professor and Senior Associate Dean for Scholarship and Research Collaborations – ASU School of Nursing and Health Innovation

    This general session will provide insight into a variety of factors related to cultural diversity that can impact how we interface and serve family caregivers across the lifespan. Learn how different cultures react differently to the burdens and stressors of caregiving, and how we can use that information to enhance our programs and the tools that we use to assess individuals of varied backgrounds and cultures.

2:30pm - 2:45pm  BREAK

2:45pm - 3:45pm  BREAKOUT SESSIONS

    Media Center West

    RESPITE CARE IN THE LGBT COMMUNITY

    **Adero Allison**, Ph.D., CEO, Transitioning Adults Plus
    And **Donna Heppermann**, MSW

    What are the specific needs of the LGBT community? And how can agencies who cater to a mainly straight demographic work together with the LGBT community to provide sensitive, affirming, and appropriate respite care to a population that may be isolated and reticent to reach out for services because of past prejudices.

    Aurora AB

    THE LIFESPAN RESPITE PROGRAM: LAYING THE GROUNDWORK FOR NEW FEDERAL PROGRAMS

    **Greg Link**, Aging Services Program Specialist, Office of Community-Based Services, Administration on Aging, US Department of Health and Human Services

    This interactive session is geared to non-grantee state government and state respite coalition representatives and other stakeholders interested in helping their state pursue their first federal Lifespan Respite Grant. Greg Link, federal program officer for the Lifespan Respite Program from the US Administration on Aging, will discuss building the groundwork for a state Lifespan Respite system.

    Aurora CD

    THE “WORK” IN SUCCESSFUL NETWORKING

    **Natalie Leek-Nelson**, CEO and President; Providence House

    The new networking goes beyond after hours of gatherings, seminars and social media. Today’s most successful networking is based on the “work” in networking. Learn how to find and engage opportunities to share your talents, ideas and work in projects, collaborative, Boards and committees that can propel you and your organization while building a network that works with, and for you.

    Cira C

    DISASTER PREPAREDNESS FOR SPECIAL NEEDS POPULATIONS

    **Sybil Ingram-Campbell**, MBA, Ph.D.

    This presentation will cover some of the plans put in place by state and local disaster planners to handle the needs of the general population during an incident contrasted against needs usually overlooked or under addressed for their respective special needs constituents.
Day One - Wednesday, November 2nd (cont.)

2:45pm - 3:45pm  BREAKOUT SESSIONS

Cascade A  TRADING AGES
Susan Cypert, B.S., Community Resource Specialist, SCAN Health Plan Arizona
The growth of the older adult population is impacting families and communities. This growth presents a unique challenge to understanding the needs, experiences and perspectives of older adults. Learning the skills necessary to work effectively and improve interactions with older adults is essential for caregivers, children, grandchildren and all those interacting with older adults.

Cascade B  FROM INDIVIDUAL ADVOCACY TO SYSTEMATIC CHANGE
Siobhan McCurdy, Education & Advocacy Coordinator, National Multiple Sclerosis Society, Arizona Chapter and Joe Rubio, Lead Organizer for Valley Interfaith Project.
Advocacy starts with you … literally! Lay the ground work for caregivers & direct service professionals to realize the important components of their work to enhance quality of life through public policies & legislation. Understand the role of direct service work in achieving successful policy change. Learn key skills to build a campaign around an issue. Identify ways which you can contribute.

Cascade C  VALUES, BELIEFS AND ATTITUDES
Marta Urbina, Chief, Office for Children with Special Health Care Needs, Bureau of Women’s and Children’s Health, Arizona Department of Health Services
Culture influences what we take for granted in our everyday lives. Every family has expectations about what life will be like when their baby is born, which must be renegotiated when confronted with a special health care need. This session is designed to promote an understanding of how our personal values and beliefs have an impact on the way we make decisions.

Cascade G  THERAPEUTIC RESPITE FOR INDIVIDUALS WITH SERIOUS BEHAVIORAL ISSUES
Mary K. Wright, LISW, CEO, Respite Connections, Inc.
Respite Connections has provided over 10 years of therapeutic respite care services to children and adults who are dually diagnosed with a developmental disability and mental health/behavioral issues. This workshop will focus on how to establish a community-based respite care program, both in the home and out of the home settings, including overnight respite and explore funding options.

3:45pm - 4:00pm  BREAK

4:00pm - 5:00pm  BREAKOUT SESSIONS
Day One - Wednesday, November 2nd (cont.)

4:00pm - 5:00pm  BREAKOUT SESSIONS

Media Center West  TRADITIONAL BELIEF SYSTEM
Connie Bremner and Carrie Bear Chief Evans, Title VI Director and Direct Support Coordinator, Blackfeet Eagle Shield Center
Learn how the National Family Caregiver Support model was adapted into the culture and traditions of the Blackfeet people. The program was developed using the Medicine Wheel as a guide; it is a traditional symbol of all things endlessly working together, and has been used by the people for thousands of years.

Aurora AB  ADVOCACY IN THESE DIFFICULT POLITICAL TIMES
Timothy J. Schmaltz, CEO, Protecting Arizona's Family Coalition (PAFCO)
Legislative advocacy has changed in the new political reality. The next years of legislative action and elections will be critical. Many traditional skills remain --- power analysis, how to make a visit, telephone call or write a letter, how to deal with legislative dodges, how to join together for united action, how to do communications with policy makers and media.

Aurora CD  THE PHYSICAL AND MENTAL CHALLENGES OF DEMENTIA-IMPAIRED PERSONS AND THEIR IMPACT ON BEHAVIOR AND CAREGIVER STRESS
Mary Fridley, RN, BSN, BC, Gero-Resources, LLC and Mary Chaput, Program Director for the Respite Care Referral & Family Caregiver Support Programs. The continuing decline in functional and cognitive abilities experienced by dementia-impaired people can make simple everyday tasks impossible to complete leading to seemingly inappropriate behaviors and causing caregiver stress. In this session participants will briefly experience living with dementia and learn how to meet the needs of the dementia person and the caregiver.

Cira C  FINDING AND KEEPING A RESPITE WORKER
Val Croissant, M.S., CTRS; Director of Respite Services, Easter Seals Wisconsin
This session is geared for Caregivers and will discuss all aspects of finding and keeping an in-home respite worker. Come learn how to thoroughly screen and train someone so that you can trust them with your loved one. This is a very informative session with lots of tips to take home and use today.

Cascade A  LAUGHTER YOGA
Karen Richards, R.N., MBA, CPHQ, SCAN Connections Resource Center, Manager SCAN Health Plan Arizona
Laughter, yogic breathing and unique exercise movements are combined to create Laughter Yoga. By laughing we initiate powerful positive changes in our body, mind and emotions. Laughter crosses all barriers and is accessible and effective for people of all ages and most physical conditions. It provides opportunities for group dynamics and social interaction and it’s good for your health.
Day One - Wednesday, November 2\textsuperscript{nd} (cont.)

4:00pm - 5:00pm

**BREAKOUT SESSIONS**

**Cascade B**

**THE THINK GROUP PROCESS FOR DEFINING “RESPITE”**

Jennifer Rosenbaum, Director, NY Lifespan Respite Grant Initiative, New York State Office for the Aging – Maureen Murphy, Director of the New York Caregiving and Respite Coalition (NYCRC). Karen Iovino, Coordinator for NY Lifespan Respite Grant Initiative.

The State of New York engaged in an innovative process to launch the Lifespan Respite Grant initiative. As a starting point, it was decided that a common definition of “Respite” needed to be established. Thus, we solicited across the Lifespan and Disability spectrum to engage in a THINK GROUP. The purpose: to define respite in a manner that allows for a complete and comprehensive inventory.

**Cascade C**

**USING DATA TO SUCCESSFULLY DRIVE YOUR PROGRAM: PROGRAM EVALUATION AND EVIDENCE INFORMED RESPITE PROGRAMS**

MaryJo Alimena Caruso, M.Ed. Coordinator, CareBreak at the Watson Institute, and Jennifer Abernathy, Tennessee Respite Coalition

This session will present two examples of respite programs using data gathered from participants to inform programmatic decisions and changes. The presenters will discuss the process of designing tools for gathering data, their experiences with gathering data, and how the results are used to guide evidence informed programming.

**Cascade G**

**INCREASING AWARENESS OF ALZHEIMER’S DISEASE AMONG ARIZONA NATIVE AMERICANS**

Filmer Lalio, MEd, Community Outreach Coordinator, Banner Alzheimer’s Institute

The incidence of Alzheimer’s disease among Arizona Native Americans is largely unknown and many tribes have lacked vocabulary to describe dementia. Banner has taken the three pronged approach to increase this in 22 tribal nations. To better understand normal cognitive aging in Native elders, an urban cohort of elders is being followed in a longitudinal study.

5:00pm

**DAY ONE CONFERENCE ACTIVITIES ADJOURNED**

6:00pm – 8:00pm

**PRESENDER’S APPRECIATION FIESTA**

**CAREGIVER HOUSE – FOUNDATION FOR SENIOR LIVING**

This event is by invitation only and separate signup. Buses load at 5:15 pm. Buses will depart from the hotel lobby at exactly 5:30 pm.
The vision of AZ4A is to prepare all Arizonans for aging.
Day Two - Thursday, November 3rd

7:30am - 4:30pm  REGISTRATION – Media Center Lobby

7:30am - 8:30am  CONTINENTAL BREAKFAST

8:30am - 9:30am  PLEINARY PRESENTATION – NETWORK BUILDING TRACK
The Ryan House Story - From family need, to vision, to respite for families!
Holly and Jonathan Cottor, Parents of a special needs child, and Co-Founders
This is the house that a community built. It took four years of ice-cream socials, car
washes and other fundraisers to come up with the $6.9 million needed to create this
facility, tucked between a parking garage and an outpatient rehabilitation center near St.
Joseph’s Hospital and Medical Center in central Phoenix. The Ryan House mission is to
provide palliative care and pediatric hospice services for children with such life-
threatening conditions as cancer, muscular dystrophy and cystic fibrosis. Parents can
stay with their kids for a few days as the staff assists with the exhausting around-the-
clock care. Or parents can take a break and spend time together elsewhere, knowing
their children are in good hands at Ryan House.

9:30am - 9:45am  BREAK

9:45am - 10:45am  BREAKOUT SESSIONS

Media Center West  CAREGIVER COOPERATIVES: CREATING YOUR OWN RESPITE CARE
Gerald Nebeker, Ph.D., The Utah Caregiver Cooperative, Inc.
There will never be enough federal or state money to meet everyone’s respite needs.
And, to make matters worse, funding in most states is being cut. In response, many
caregivers are organizing or joining caregiver cooperatives. Three successful
cooperative models will be presented that either made state funding go further or
utilized private funding in order to help meet caregiver respite needs.

Aurora AB  RELATIONSHIPS ENSURE SUCCESSFUL PARTNERSHIPS
Phyllis Stephenson, North Carolina Respite Care Coalition and Easter Seals UCP NC
and VA, and Alicia Blater, Lifespan Respite Project Director, North Carolina Division of
Aging and Adult Services
This session defines roles of the State Respite Coalition and Division of Aging. Role
definition, partnerships and network building, integration and expansion will be
exemplified. This will be an interactive workshop with a goal of participants creating
action plans for their states! The goal will be an involved, fun learning exchange to
inspire respite growth.
Day Two - Thursday, November 3\textsuperscript{rd} (cont.)

9:45am - 10:45am  
**BREAKOUT SESSIONS**

**Aurora CD**  
**THE RESPITE LEARNING PORTAL**  
*Leslie Atkinson*, Executive Director, SafeGuards Training  
The Respite Learning Portal provides a dynamic place for knowledge exchange for respite caregivers and families to enhance the quality of care. The Learning Portal builds on a foundation of key values, communication, roles, quality relationships and boundaries essential in supporting continuity of care. Learn more about effective online training, webinars, discussion boards and resources.

**Cira C**  
**INNOVATIVE WAYS OF SUPPORTING COMPLEX BEHAVIORS WITHIN RESPITE**  
*Carrie McEachran*, Director, Respite Services, *Connie Smits*, Supervisor, Adult Respite Services, *Kristy Bond*, Supervisor, Children’s Respite Services  
Providing creative and innovative ways of carrying out appropriate and high quality respite options for individual’s with complex behaviors isn’t always an easy task. Faced with an increase of respite requests for these high needs individual’s, Community Living Sarnia Lambton needed to come up with creative approaches in supporting these individual’s and their families to ensure success.

**Cascade A**  
**PARTNERING WITH YOUR STATE’S TITLE V PROGRAM**  
*Joy C. Liebeskind*, Statewide Coordinator, CT Lifespan Respite Coalition  
Learn how your coalition can partner with your state’s Title V SCSEP program. Get money for respite care using Title V and support more caregivers. Learn the 7-components. Get funding for Respite Care in your state!

**Cascade B**  
**DISASTER PREPAREDNESS, OR HOW TO BUILD SAFETY NET**  
*Stacey C. F. Martinez*, Self-Service Respite Program Manager, Bay Respite Care  
While the thought of a disaster is stressful and scary, being prepared can help relieve anxiety, keep you focused and save your loved ones. This workshop will give you, your family, your Respite Care Provider and your community the tools needed to build a safety net, which in turn will create piece of mind for you.

**Cascade C**  
**NETWORKING SESSION**  
Opportunity to meet with representatives of grantee states.

**Cascade G**  
**THE VOUCHER MODEL FOR DELIVERY OF RESPITE SERVICES**  
*Java Bennett*, Director of Respite Services, United Cerebral Palsy of Huntsville and Tennessee Valley, Inc.  
The voucher method is considered "best practice" for delivery of respite to families by maximizing available funding and allowing the family flexibility regarding when to take respite and whom to provide the service. This session will discuss several sources that may provide voucher funding, offer start up forms and discuss the administration of a voucher program.
Day Two - Thursday, November 3\textsuperscript{rd} (cont.)

10:45am - 11:00am  BREAK

11:00am - 12:00pm  BREAKOUT SESSIONS

Media Center West  

**ENHANCING QUALITY OF LIFE FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS**  
Jan Dougherty, MS, RN, Director, Family and Community Service, Banner Alzheimer’s Institute  
Living with a chronic illness like Alzheimer's disease AD/dementia can pose an increased risk toward social isolation and decreased quality of life for both the affected person and the caregiver. Finding safe, comfortable, and rewarding experiences that promote joy and meaning are needed. Banner Alzheimer’s Institute has created a number of unique community-based programs to help.

Aurora AB  

**TRANSFORMING CRISIS NURSERY CARE (PART A) - ACTION, ADVOCACY, ACCESS**  
Natalie Leek-Nelson, CEO and President; Providence House  
Learn how the Crisis Nursery’s role in child abuse prevention, crisis respite, and emerging new multi-generational and multi-systemic crises require a revised view of Crisis Nursery service delivery and the need to transform the traditional model through agency and community action, public and private sector advocacy, and enhanced accessibility for clients and practitioners.

Aurora CD  

**USING DATA TO SUPPORT AN INNOVATIVE RESPITE NETWORK IN DELAWARE**  
Barb Snyder, Project Manager, DE Lifespan Respite Care Network; Janet Harper-Wooley, Senior Social Worker/Case Manager, CARE Delaware, Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)  
Delaware Lifespan Respite Care Network has from its inception used data to help identify needs, develop services, and measure ongoing satisfaction and outcomes for family caregivers. This session will provide information about the tools that were used including caregiver and provider surveys, and how data continues to be used to assure best use of resources using surveys of service recipients.

Cira C  

**HIGH BURDEN SELF-IDENTIFIED FAMILY CAREGIVERS ACROSS THE LIFESPAN: A NICHE POPULATION BOTH FEISTY AND IN NEED**  
Suzanne Mintz, President/CEO, National Family Caregivers Association  
This session will provide attendees with insights into a subset of family caregivers, those who are both high burden and self-identified. Survey results include: demographics, needs, impact and more. Comparison made with “typical” family caregivers to note similarities and differences. Results point to unmet needs and potential programming opportunities to meet them.
Day Two - Thursday, November 3rd (cont.)

11:00am - 12:00pm
Cascade A

**BREAKOUT SESSIONS**

**BUILDING TRUST IN RESPITE CARE**
Sherylynn Laich, Executive Director, UPTOHIM™ Ministries and Joy Matson, Board Member UPTOHIM™ Ministries
Respite care necessitates the establishment of trusting relationships. Participants will discuss the common fears, anxieties and vulnerabilities associated with establishing and providing respite care, will learn the four necessary components to establishing trust, and will begin to develop compassion-based respite care plans.

Cascade B

**COMMUNITY BASED AND SUPPORTED RESPITE PROGRAMS**
Tonya Frye, Executive Director, Desperate for Respite
This session will enable you to create community-based and volunteer supported respite care and support programs. You will be given the tools necessary to motivate police, fire, rescue and other professionals within your community to support caregivers’ families. Create a safer, smarter and more diverse community.

Cascade C

**OUTCOMES BASED PROGRAM EVALUATION**
Vidya Sundar, Ph.D., Institute on Disability/UNH, Durham, NH
Transitions in Caregiving is a consumer-directed program aimed to empower caregivers of older adults to identify and manage their own support needs. Learn about planning and implementing a program with Outcomes Based Evaluation.

Cascade G

**BUILDING LOCAL AND STATE LIFESPAN RESPITE NETWORKS**
Sharon Kaiser, Early Childhood Systems Program Specialist, Special Medical Services, Title V, CSHCN
Building networks for Local and State Lifespan Respite Coalitions for sustainability of the Lifespan Respite Program including trained providers and incorporate the needs into planning. Utilizing identified Stakeholders to gather the needs of caregivers and develop relationships.
Day Two - Thursday, November 3rd (cont.)

12:15pm – 1:15pm
Media Center East

LUNCH / NETWORKING

1:15pm - 1:45pm
Media Center West

PLENARY PRESENTATION

Laughter is Respite!
Elaine Lundberg, Laughter Therapist
Humor Therapist Elaine M. Lundberg takes a humorous yet practical approach to wellness and stress management. She educates, motivates and helps professionals; agencies, companies and caregivers learn to effectively incorporate positive humor into their personal lives and their professional life. Come prepared to lighten up, laugh and learn how to take a respite.

1:45pm - 2:30pm
Media Center West

PLENARY PRESENTATION – SERVICE DELIVERY OPTIONS TRACK

The Many Faces of Respite Services!
Guy Mikkelsen, President and CEO, Foundation for Senior Living
This address will focus on the varied ways that we serve family caregivers from different cultures and with different needs. How do we incorporate consumer direction into our service networks and retain quality and control? How do we create partnerships with faith-based organizations that add both capacity to the network and solutions to trust issues that lead to refusal of respite services? Here ideas about these topics and more!

2:30pm - 2:45pm

BREAK

2:45pm - 3:45pm

BREAKOUT SESSIONS

Media Center West

INDEPENDENT MONITORING FOR QUALITY: AN EVIDENCE-BASED STRATEGY FOR BUILDING AND SUSTAINING EFFECTIVE PROGRAMS
Guy Caruso, Ph.D., Western Coordinator, Institute on Disabilities at Temple University, and MaryJo Alimena Caruso, M.Ed., CareBreak at the Watson Institute
Pennsylvania’s Statewide Independent Monitoring for Quality program has people with disabilities, family & community members interview 6,000 people yearly in a variety of settings to promote continuous quality improvement (CQI). This evidence-based process can be adapted for respite programs to understand & address participant respite needs and generate useful data to inform programs and share policy.

Aurora AB

TRANSFORMING CRISIS NURSERY CARE (PART B) - PROGRAMS, PEOPLE, PLACES
Natalie Leek-Nelson, CEO and President; Providence House
Crisis Nursery care is changing. Programs, staff and facilities must also change to meet the new and emerging role that Crisis Nurseries can and will play in addressing child safety, family stability and long-term self-sufficiency for the Nursery and the families they serve. Learn about a new Crisis Nursery 3-phase transformation plan integrating service, succession and sustainability.
Day Two - Thursday, November 3rd (cont.)

2:45pm - 3:45pm  BREAKOUT SESSIONS

Aurora CD  SHARING THE CARE: UTILIZING VOLUNTEER COUNCILS FOR RESPITE AWARENESS, NETWORKING AND CAPACITY BUILDING WITHIN LOCALIZED COMMUNITIES.
Linda Lamberth, Program Manager, Alabama Lifespan Respite Resource Network and Java Bennett, Director of Respite Services, UCP of Huntsville and Tennessee Valley, Inc. and Melissa Enfinger, MS, Respite Project Coordinator Alabama Respite
Using Lifespan states as the model, Sharing The Care (STC) is an innovative alternative to state funded infrastructures by developing regional volunteer councils that work to increase respite awareness, develop new community-based resources, and inform policy makers about local needs. Alabama Respite currently coordinates five of these councils throughout the state.

Cira C  TRANSFORMING VA’S RESPITE CARE PROGRAM
Daniel Schoeps, Veterans Affairs
VA has transformed its HCBS-Respite Program to better serve caregivers and Veterans of all ages. The Program is open to new service models of respite through its partnership with the aging/disability/respite networks. Expansion of respite is part of VA’s effort to balance its LTC services. Session explores program re-structuring and how to participate, the centrality of working partnerships.

Cascade A  SURVIVOR: HOW TO KEEP YOUR TORCH BURNING!
Barbara Donati and Joan Kelly Rafferty, Co Directors of the Central Massachusetts Respite Project (CMRP)
Are you dreading that you will be the next one to be voted off the island and your torch extinguished? This workshop will explore strategies to advocate for your program, build capacity, and promote sustainability. Hear the success story of how the Central Massachusetts Respite Project avoided extinction and remains a viable and effective respite program.

Cascade B  LAUGHTER THERAPY/REDUCE STRESS
Lyne Petersen, Independent Living Advocate-Arizona Bridge to Independent Living (ABIL)
Laughter Therapy has been taught in India for over 5000 for healing. Laughter Therapy was introduced in 1997 to the Western Hemisphere and now is a Certified program. There are many benefits to "Laughter" especially as a Stress Reliever; however others are: to reduce blood pressure, Improve the Immune System, and generally It makes us Feel Good! Besides, it’s Fun!

Cascade C  ACCEPTING & ACHIEVING RESPITE
Cheryl Dinnell, Coordinator, Nevada Lifespan Respite Care Program
Reaching consensus on how respite is described and when it’s achieved is important. Respite is achieved in many ways but it’s not something family caregivers accept easily, even if they know they need it. To accept respite, caregivers will go through a preparatory process that programs and agencies need to understand and facilitate.
Day Two - Thursday, November 3\textsuperscript{rd} (cont.)

2:45pm - 3:45pm  **BREAKOUT SESSIONS**

Cascade G  **INNOVATION IN SUCCESSFUL COLLABORATIVE IMPLEMENTATION OF WEB-BASED RESPITE REGISTRY**

Jeffrey A. Keilson, Vice President, Rewarding Work Resources, Inc. and Elenore Parker, President and co-founder of Rewarding Work Resources.

Retaining respite workers on an ongoing and emergency basis is a challenge for caregivers and the people they care for. This session will focus on benefits of a web-based registry developed and promoted through coalitions of key stakeholders, including government agencies, independent living centers and area agencies on aging. A Respite Registry provides needed support for caregivers.

3:45pm - 4:00pm  **BREAK**

4:00pm - 5:00pm  **BREAKOUT SESSIONS**

Media Center West  **THIS ROOM IS DARK DURING THIS SESSION**

No Workshop Scheduled Here

Aurora AB  **CREATING THE CARING NETWORK TRAINING: TRAINING PROGRAM FOR IN-HOME PROVIDERS**

Val Croissant, M.S., CTRS, Director of Respite Services, Easter Seals Wisconsin

Wisconsin created the Lifespan Caring Network Training Program, which gives respite providers comprehensive information covering the basics of providing in-home respite care. This session will talk about the steps that Wisconsin took in creating a baseline program, including the process of working with outside agencies, writing the material, finding resources, registration and marketing.

Aurora CD  **RESPITE IS AS INDIVIDUAL AS YOU AND YOUR SITUATION**

Kelley Reese, Regional Coordinator, Volunteer, Well Spouse Association

Caregiving takes on many forms so “Respite” can mean different things to each individual. Define your “normal”, know yourself and then find the right respite for you. For some it’s finding solitude, for others it’s socialization and sometimes it’s both. Respite can be 5 minutes or a week, so don’t confine yourself to one solution.

Cira C  **NATIONAL RESPITE COALITION POLICY UPDATE: ADVOCACY FOR THE 112\textsuperscript{TH} CONGRESS**

Jill Kagan, MPH, Chair, ARCH National Respite Coalition and Program Director, ARCH National Respite Network and Resource Center

Overview of federal caregiving and respite funding and policy issues upcoming in the 112th Congress, focusing on the reauthorization of the Lifespan Respite Program. Participants will also have an introduction/refresher on honing your advocacy skills.
Day Two - Thursday, November 3rd (cont.)

4:00pm - 5:00pm  BREAKOUT SESSIONS

Cascade A  INNOVATIVE WAYS TO “CONNECT” CAREGIVERS WITH RESPITE WORKERS
Louise A. Bruce, Founder & Volunteer Executive Director of The LaChris Connection (TLC)
Find Respite! Familiar with relentless attempts to match-up your family’s needs with a helper? Can’t connect with one another? Tired that 1:1 interviews don’t reveal much and other dead-ends? Learn of fresh, proven models where fatigued caregivers are introduced to respite providers in a pleasant setting! Hear about “Meet the Parents” mixers, agency collaboration & care.com/TLC services!

Cascade C  SMALL COMMUNITY...BIG IMPACT
Rachel Minton, R&R Respite Care Program Manager, Area Agency on Aging, Region One
Learn how small, rural communities can maximize resources to provide group respite services in an adult day care setting. Through the commitment of community leaders and residents alike, a small rural Arizona town came together to build and sustain the R&R Respite Care Center to serve older adults and their caregivers.

Cascade G  IMPROVING HEALTH AND QUALITY OF LIFE FOR TODAY’S CAREGIVERS: HEALTHY LIVING (CDSMP) IN ARIZONA
Melanie Mitros, Ph.D., Director, Arizona Living Well Institute
This workshop will detail an evidence-based chronic disease self-management program that is having a positive and empowering effect on people’s lives. Healthy Living is a 6 week workshop that increases self-management skills to improve quality of life of the caregiver and those they care for. It is an advantageous activity for caregivers to partake in while they are receiving respite care.

5:00pm  CONFERENCE ACTIVITIES ADJOURNED

7:00pm – 9:30pm  PHOENIX COYOTES HOCKEY GAME - JOBING.COM ARENA
Use the coupon included in your conference bag to get a significant discount to attend this exciting event within a very short walking distance of the hotel. The arena is a great venue and even if you’re not a hockey fan, guaranteed you’ll have fun!
The California Respite Association thanks Arizona for hosting the 2011 National Lifespan Respite Conference!
We are a voice for spousal caregivers. Our group, the Well Spouse™ Association (“WSA”), is the only nonprofit organization in the USA dedicated solely to the support of this special segment of caregivers; and is not disease specific. The personal issues of a spousal caregiver are unique, dramatic, and, for the most part, ignored by society and medical institutions. The physical and financial challenges of caring for one’s life partner, usually unable to work or share in the household responsibilities, are painfully augmented by emotional stress, social isolation, and the sad mutation of the couple’s rapport. WSA has a strong presence on the east coast but our desire is to grow accessibility and awareness right here in Arizona and the southwest region of the United States. Know a spousal caregiver? Why not give them a gift of membership? We welcome new members from everywhere. Visit us at www.wellspouse.org

Special thanks to Western Refining, Inc. for fueling our efforts in Arizona.
Grantee’s Meeting - Friday, November 4th
(Lifespan Respite Grantee States Only – Separate Registration Required)

8:30am - 9:00am  CONTINENTAL BREAKFAST
Solana A

9:00am - 9:15am  WELCOME AND INTRODUCTIONS
Solana B,C,D

9:15am - 9:45am  GREG LINK
What to expect from AoA and AoA’s Vision for the Future of Lifespan Respite

9:45am - 10:15am  CASANDRA FIRMAN, FRIENDS NATIONAL RESOURCE CENTER
Evaluation tools for lifespan respite

10:15am - 10:30am  BREAK

10:30am - 11:15am  SMALL GROUP DISCUSSIONS – SESSION ONE
- How to get Started (for newest grantees)
- Marketing Respite Message
- Sharing Data Collection Tools
- Building State Respite Coalitions/Strengthening Partnerships

11:15am - 12:00pm  KATHY KELLY
Overview of Caregiver Assessments and Relevance to Respite with Q and A

12:00pm - 12:45pm  LUNCH
Solana A

12:45pm - 1:00pm  JILL KAGAN
- Federal Funding to Sustain Programs and Promote Partnerships
- National Respite Locator State Pages
- New Fact Sheets

1:00pm - 1:45pm  SMALL GROUP DISCUSSIONS – SESSION TWO

1:45pm - 2:00pm  MAGGIE EDGAR
Introduction to New Respite Guidelines

2:00pm - 2:45pm  SMALL GROUP DISCUSSIONS – SESSION THREE

2:45pm  WRAP-UP
Thanks to our Volunteers and Supporters!
PRESENTER PROFILES
(alphabetically by last name)

JENNIFER ABERNATHY The Executive Director of the Tennessee Respite Coalition, an organization that provides respite services and information to family caregivers across the state. She has diverse professional experience working in the fields of disability, mental health, volunteer management, senior services, and higher education.

DR. ADERO ALLISON has worked in the field of human services for over 32 years. The company she heads advises clients who are transitioning from home to assisted living, nursing home, etc. She helps them to move, find appropriate housing, and offers emotional counseling. Dr. Allison, an ordained minister, is a charter member of the LGBT Boomers & Beyond Coalition in Phoenix, Arizona.

MARY BEALS LUEDTKA Mary began her career in the aging field at Northern Arizona Council of Governments Area Agency on Aging (NACOG AAA) in 1991 developing and implementing three advocacy programs, Legal Advocacy for Seniors, Benefits Counseling, and the Long Term Care Ombudsman. In 1994 the Programs grew to create the Elder Rights Unit and Mrs. Luedtka was promoted to the position of Elder Rights Unit Supervisor overseeing all three programs and coordinating the Legal Advocacy Program. Mary Beals Luedtka is a member of numerous boards and organizations that focus on the Mission she promotes: “To maximize the independence and dignity of older persons and advocate for the needs and rights of older citizens, their families, and their caregivers.”

JAVA BENNETT served as Program Director for United Cerebral Palsy of Huntsville and Tennessee Valley in Huntsville, Alabama (UCP), for 15 years, and has served as lead for Alabama’s Respite Resource Network project since it began in 2000. She is a graduate of Mississippi State University in Special Education and holds a license in the State of Alabama in Social Work. Mrs. Bennett has worked with children who have disabilities and their families in a variety of roles for over 30 years. Java has three sons and lives in Huntsville, Alabama.

ALICIA BLATER works as the Lifespan Respite Project Director for the North Carolina Division of Aging and Adult Services. Phyllis Stephenson has worked with the North Carolina Respite Care Coalition since 1997. She also has experience in working with individuals across the life span and currently serves as a Child and Family Services Director for Easter Seals UCP NC & VA

CONNIE BREMNER AND CARRIE BEAR CHIEF EVANS Director of the Title VI Nutrition Program and Family Caregiver Support Program, Elder Protection 3 Team Committee Member, and Director the Blackfeet PCA Program, a Medicaid Reimbursement Program that brings in $1,000,000 in reimbursements each year. They were recently selected to represent American Indians at the White House Conference on Aging and Serves as a consultant to many Aging Service organizations.

LOUISE A. BRUCE parented three children, including two born with cerebral palsy. Lifelong involvement in social services combined well with her desire to make a difference in the community of families with special needs. The Bruce family founded “The LaChris Connection”, and TLC’s mission is to ensure that families have easy access to care providers, respite, and adventure that bring health to parents, marriages and families.

DR. GUY CARUSO, as Western Coordinator, is responsible for coordinating Institute training and related activities in the western part of Pennsylvania. He works on a number of Institute grants and provides technical assistance to the Pa OMR Independent Monitoring for Quality Program. Guy has worked in human services for 32 years in a number of capacities – advocate, teacher, trainer, researcher, and consultant.
MARYJO ALIMENA CARUSO manages CareBreak, a respite program of The Watson Institute that identifies, screens, trains, and matches volunteers to provide respite care for families of children with disabilities. MaryJo facilitates trainings nationally in the areas of respite program and coalition development, child welfare, person and family centered planning and disability issues.

MARY CHAPUT is the Program Director for the Respite Care Referral & Family Caregiver Support Programs at the Anne Arundel County Department of Aging & Disabilities in Maryland. She holds a Bachelors of Arts degree in Human Services and a Master of Arts in Studies in Aging from the Notre Dame of Maryland University. Mary’s passion and focus is to provide information and support services to family caregivers in the hope that she can help them on their caregiving journey.

VAL CROISSANT, M.S., CTRS is the Director of Respite Services for Easter Seals WI and has a master’s degree in Therapeutic Recreation. She has been responsible for screening and training over 100 staff every year in working with campers with severe disabilities. She has presented at numerous conferences and is the creator of the Lifespan Caring Network Training for Respite providers.

SUSAN CYPERT provides cutting edge health education programs for the geriatric and physical challenged populations, SCAN members and the community at large.

ELISA DAVIS Elisa Davis has been an Area agency on Aging Director for Western Arizona Council of Governments for a combined total of over ten years. She has also served as the Executive Director of a large five county Community Action Agency in southeastern New Mexico for over ten years where she was responsible for programs funded under the Older Americans Act, Head Start, Community Services, Child and Adult Care Food Program, Rural Housing and Economic Development, Foster Grandparent and Senior Companion. Elisa holds a Bachelor’s in Criminal Justice and a Masters in Public Administration.

TISHA M. DIFFIE, in 2009 Tisha and husband Larry founded After the Fact – Final Affairs, LLC after she had to handle her 3rd estate closure. She saw that many other families needed assistance and had nowhere to turn. In 2010, she sold her financial planning practice to focus 100% on assisting other families that were overwhelmed with handling the final affairs.

CHERYL DINNELL is a family caregiver and uses respite services. She has a son with multiple disabilities. Her work at the University Center for Excellence in Developmental Disabilities in peer mentoring and leadership development training led to advocacy roles on several state level boards and commissions, in addition to the position as Coordinator of the Nevada Lifespan Respite Care Program.

BARBARA DONATI is the Co-Director of the Central Mass Respite Project and the parent of a young woman with Autism.

JAN DOUGHERTY is Family and Community Services Director at Banner Alzheimer’s Institute. She serves patients with dementia and their families through the development and implementation of innovative programs including early stage programming, arts and dementia, an array of caregiver education programs and Native American Outreach. She also pioneered efforts in “Hospice Care for Dementia” and “Palliative Care for Advanced Dementia” which has resulted in major changes in care practices for persons with advanced dementia. Jan completed her BSN from Valparaiso University and her MS in Gerontological Nursing from the University of Arizona. Jan was named “Gerontologist of the Year” in 2003 by the Arizona Geriatrics Society and received the “Caring Spirit Award” in 2005 from the Area Agency on Aging, Region One.
MELISSA ENFINGER serves as Respite Project Coordinator, developing STC initiatives in South Alabama. Mrs. Enfinger holds BA degree in Psychology and Communication Studies and a MS degree in Management of Non-Profit Human Service Organizations. Melissa has worked in the field of residential services and supports for persons with intellectual and developmental disabilities for twelve years. Melissa is a wife, caregiver, and the mother to one son, Ethan. She and her family live in Millbrook, Alabama.

MARY C. FRIDLEY, RN, BC is the owner of Gero-Resources, LLC a business dedicated to empowering caregivers, preventing elder abuse, and promoting successful aging through education. She is a registered nurse board certified in gerontology with more than 25 years in the geriatric health field. Mary is a successful caregiver advice columnist, speaker, educator, and consultant specializing in caregiving, eldercare, and aging with expertise in dementia care.

TONYA FRYE Founder and Executive Director For Respite: Caregiver Outreach, developed ACT (Accessible Care Teams), programs where community volunteers “Adopt-a-Caregiver” provide support, education, awareness, friendship, and crisis respite. Also developed SIR (Schedule It Respite) program where caregivers can make an appointment for respite so they can care for their own needs, with a start date of November 2011.

SCOTT HAWTHORNTHWAITE is a graduate of Arizona State University School of Social Work and has worked at the Area agency on Aging for over 9 years. Scott was a Peace Corps volunteer in Honduras where he worked as a health educator. He has 25 years of case management experience including management positions with two Medicaid (ALTCS) Long Term Care providers in Arizona. Before coming to work at the agency, Scott was the Program Manager for the Agency’s contracted non- medical home and community based services program. Scott is the Director of Care Coordination at the Area Agency which includes managing the Family Caregiver Support Program.

DONNA HEPPERMANN was Director of Caregiver Services for Duet in Phoenix for the past 22 years. She retired this past summer. While at Duet she began a program for kinship caregivers, led the Arizona Kinship Care Coalition, and, 3 years ago, along with the Area Agency on Aging, Region One, began the LGBT Boomers and Beyond Coalition.

DR. SYBIL INGRAM-CAMPBELL is a respected and experienced professional in the areas of healthcare information systems and regulatory compliance issues. Dr. Ingram-Campbell has served as a clinician, clinical researcher and instructor, emergency preparedness and readiness specialist as well as serving as an independent validation and verification compliance manager for multiple national providers of healthcare services. As a volunteer, she is an active Georgia state representative for the National Family Caregivers Association.

KAREN IOVINO has over 23 years of service in the Aging Network through the NYS Office for the Aging. She has been engaged in family caregiver-related policy development for five years, as Coordinator of the New York State Family Caregiver Council, as well as Coordinator for all aspects of the state’s efforts on Lifespan Respite. Karen is the Coordinator of the New York State Lifespan Respite Grant Initiative, as well as the Coordinator for the NYS Family Caregiver Council.

SHARON KAISER has 45 years experience as a Pediatric Nurse with a specialty in young children and children with special health care needs. She currently serves on the Board of Directors for Early Education Intervention Network and works on many initiatives across State and Local agencies/programs.

JEFF KEILSON, a nationally known consultant to government and private agencies in self-determination and self-advocacy, is the former Regional Director for the Metro Region of Massachusetts, providing supports to more than 9,000 individuals and families. He presently is Vice-President of Rewarding 3 Work Resources and Advocates, Inc., a 35-year old private agency that serves more than 20,000 people.
SHERLYNN LAICH is the Executive Director of UPTOHIM™ Ministries, a faith-based non-profit that supports and educates caregivers of loved ones with Parkinson’s, dementia, and Alzheimer’s. She is a retired attorney, a trained Advocate with the Alzheimer’s Association, assists in resolving disputes through biblically-based conflict resolution methods, and is a full-time caregiver to her parents.

FILMER L. LALIO, (Zuni Tribe) is the Community Outreach Coordinator for Family and Community Services, Banner Alzheimer’s Institute and he coordinates the Native American Program for Banner Alzheimer’s Institute. He is responsible for providing Alzheimer’s and Dementia education and awareness campaign to the 22 Arizona Native American Tribes and Urban Indian programs and community organizations. He collaborates and coordinates culturally appropriate workshops and presentations in Native American communities as well as outreach with Flagstaff, Tucson and Phoenix programs.

LINDA LAMBERTH has twenty-five years in social service related fields. She has been Program Manager of the Alabama Lifespan Respite Resource Network since 2000 and has taken the program from its infancy to its current status as Alabama’s leading organization to address respite issues statewide. Her work includes educating legislators on the need for funding for respite and speaking to caregivers and organizations on the importance of taking respite. She lives in Anniston, Alabama and is the mother of three and grandmother to three. Linda is currently working on her degree in Public Relations and Communications.

NATALIE LEEK-NELSON has 20 years of experience in nonprofit and corporate environments focusing on P.R, marketing, program development, IT, and fundraising. Since assuming her role as Providence House CEO, she has worked to improve the quality of the Crisis Nursery Model as an alternative service model for child abuse prevention and family preservation which she has presented at numerous national conferences.

JOY LIEBESKIND is the statewide coordinator of the Ct Lifespan Respite Coalition. As the parent of 2 young adults both with Special Health Care Needs, she has had an interest in her states program for Children and Youth With Special Health Care Needs for a number of years. The Ct Coalition has had a contract for the last 5 years to perform the Respite and extended services piece of Medical Home.

STACEY C. F. MARTINEZ has worked with dozens of DD kids as a Respite Care Provider since 1998. In 2004, Stacey became a Program Coordinator for Bay Respite Care and two years later she helped start up the agencies newest respite program: Employer of Record. In order to serve California’s Latino population, Stacey has learned Spanish and teaches both Spanish and English CPR/FA classes to Respite Care Providers.

JOY MATSON serves on the UPTOHIM Ministries Board, she also is a current Board Member of H.I.M. Ministries (Home Improvement Ministries), a ministry dedicated to building strong relationships, and the Abarcca Chile Missions Board. She holds an AA degree in Nursing and a Bachelor of Science in Christian Ministry from Crown College. Ms. Matson has served her community and church in a myriad of ways.

SIOBHAN MCCURDY traveled to D.C. in 2008 with the Alzheimer’s Association to share her story of caregiving with lawmakers. In 2009 she completed the Arizona Political Leaders Fellowship with the Center for Progressive Leadership. For nearly 3 years she has worked for the National MS Society Arizona Chapter constructing a statewide advocacy program while cultivating & mobilizing a grassroots base of advocates.

CARRIE MCEACHERAN, CONNIE SMITS AND KRISTY BOND are all Manager’s in the Respite program at Community Living Sarnia-Lambton in Ontario, Canada. They began attending annual conferences in 2009, where they have learned so many useful ways of promoting and providing respite options. They made the decision to hopefully one day share their respite experiences with everyone at the conference.
**RACHEL MINTON** is the Program Manager of the R&R Respite Care Center, an Area Agency on Aging, Region One program. Rachel has worked with the elderly population for the past 15 years and has a passion for improving the quality of care and the quality of her clients lives. Rachel is originally from Kentucky and moved to Arizona in 2004 to be closer to her family.

**SUZANNE MINTZ** is an honored social entrepreneur who took a personal experience, her husband’s diagnosis of MS and its ensuing impact on their lives and co-founded the National Family Caregivers Association (NFCA) in 1993. Over the years she built it into the nation’s premier organization in support of all family caregivers, regardless of their loved one’s age or diagnosis.

**DR. MELANIE MITROS** has over 8 years of experience working with health promotion and disease prevention programs, specifically regarding program development and evaluation for older adults. She received her Ph.D. in the Interdisciplinary Physical Activity, Nutrition, and Wellness Program at Arizona State University for her research evaluating a community-based falls prevention program.

**MAUREEN MURPHY** is the Director of the New York Caregiving and Respite Coalition (NYCRC). Maureen’s has worked with Lifespan of Greater Rochester Inc., the sponsor of NYCRC, since 2007. Her work has included Program Design, Geriatric Social Work and Fraud Prevention for Older Adults. Maureen has great enthusiasm for the work of the New York Lifespan Respite Grant Initiative and the importance of a strong coalition. She has helped to grow membership in NYCRC from 200 to 400 in less than one year.

**DR. GERALD NEBEKER** has over 24 years' experience as the President/CEO of a nonprofit organization that supports people with disabilities and older persons. An expert in the field of self-directed supports, he has conducted several research studies and presented numerous times at national conferences. He is also a caregiver for his 90 year-old mother and his 10 year-old daughter with disabilities.

**ELENORE PARKER** is President and co-founder of Rewarding Work Resources, Inc., a nonprofit corporation. Prior to founding Rewarding Work, Parker was president of Parker & James Communications, an award-winning marketing company, which was the recipient of the Super Bell — the highest achievement in regional public relations — from the Publicity Club of New England. Parker earned her B.S. and M.S. in education from the University of Massachusetts. Parker is the parent of a son with developmental disabilities.

**LYNN PETERSON**, is a Licensed Laughter Therapist who has the ability to make anything "Fun". One of her many loves is to meet new people, and learn new things. Her philosophy for life is: We make no mistakes, Only correctible errors. Lyne received her certification in 1995, and has conducted 500 sessions.

**JOAN KELLY RAFFERTY**, OTR/L, is the co-director of the Central Massachusetts Respite Project and Project Coordinator of the Massachusetts Lifespan Respite Coalition.

**KELLEY REESE** has walked various paths in caregiving, as a child caregiver, a parent and a spouse. She works full time in business but volunteers with Well Spouse Association, a nonprofit organization that helps connect spousal caregivers to resources and other caregivers for support.

**KAREN RICHARDS** is the manager of SCAN’s Connections Resource Center, which provides cutting edge health education programs for the geriatric and physical challenged populations, SCAN members and the community at large.
JENNIFER ROSENBAUM is the Director of the New York State Lifespan Respite Grant Initiative, as well as the Director for the Bureau of Policy Analysis, Research, and Management for the NYS Office for the Aging in Albany, New York. She has over 24 years of service in the Aging Network through the NYS Office for the Aging. Jennifer has been engaged in policy and program development on a range of home and community based services issues, including family caregiving.

JOE RUBIO is Lead Organizer for Valley Interfaith Project, Arizona Interfaith Network Senior Organizer since 2004. Joe has been a community organizer with the Industrial Areas Foundation since 1992, working in Texas and Arizona to develop grass roots leadership to impact neighborhood, community, state and national policies.

BARB SNYDER represents a public-private partnership in Delaware. Barb, of Easter Seals, has been the project manager for the development of the DE Lifespan Respite Care Network.

PHYLLIS STEPHENSON is a Project Director for the North Carolina Respite Care Coalition and Easter Seals UCP NC and VA and Alicia Blater - Lifespan Respite Project Director, North Carolina Division of Aging and Adult Services.

VIDYA SUNDAR, Ph.D., is a currently a Research Associate at the Institute on Disability. She is responsible for providing research and evaluation support to programs at the IOD. She has extensive experience working with disability advocacy agencies and a strong background in evaluation and research including the use of measurement models in disability research.

MARTA URBINA started her new role as Chief of the Office for Children with Special Health Care Needs (OCSHCN) at the beginning of January. Marta previously served as OCSHCN’s Clinical Programs Executive Coordinator, guiding parent and youth leadership, coordinating staff activities related to family support and community development, chairing the cultural competence committee, and overseeing information.

JANET HARPER-WOOLEY has worked with Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) for 18 years. The majority of time has been working with Adult Protective Services, seeing the need for support such as respite to prevent abuse. She currently is working with CARE Delaware, the state’s Family Caregiver program through AoA.

MARY K. WRIGHT, LISW, CEO of Respite Connections, provides therapeutic lifespan respite care for individuals with more severe behavioral issues, duel diagnoses, autistic children and deaf individuals in supportive living. She is a therapist trained in DBT, Client Centered and Strength-based treatment interventions.
KEYNOTE SPEAKER BIOGRAPHIES
(Alphabetically)

DAVID W. COON, Ph.D., is the Associate Vice Provost for Health Outcomes@ASU and Senior Associate Dean, Professor, and Virginia G. Piper Charitable Trust Faculty in the College of Nursing & Health Innovation at Arizona State University. He previously served as the Associate Director of the Older Adult Center of the VA Palo Alto Health Care System and Stanford University School of Medicine and Research Scientist at UCSF/Mt. Zion Institute on Aging in San Francisco. Dr. Coon designs and implements a variety of intervention projects, such as CarePRO, that focus on diverse groups of midlife and older adults with Alzheimer’s disease or other chronic illnesses and their family caregivers. A fellow of the Gerontological Society of America, Dr. Coon’s work has been funded through federal and foundation grants, including the National Institute on Aging, the National Cancer Institute, and the U.S. Administration on Aging and it appears in variety of national and international scientific journals.

HOLLY AND JONATHAN COTTOR co-founded Ryan House after experiencing exceptional care for their youngest son, Ryan. Originally from Arizona, the Cottor family was living in England when Ryan was born and subsequently diagnosed with Spinal Muscular Atrophy, the leading genetic killer of children under two. Soon after Ryan’s diagnosis, the Cottors were referred to Helen House, the first children’s hospice in the world, where they turned for friendship and much-needed respite. When the Cottors returned to the United States in 2003, they were surprised to learn that only one such house, George Mark Children’s House, existed in the United States. They began passionately talking about their Helen House experiences, and started their new journey to inspire and rally the Arizona community together for the development of this unique model for pediatric palliative and respite care: Ryan House. Jonathan has spent his professional career working in various marketing management roles with companies and brands including Dial Soap, Breyer’s Ice Cream, Pillsbury, and General Mills. He likes to say that the Doughboy sent his family to England and Betty Crocker brought them back to Arizona. His strong passion and marketing background proved very useful in the early days of Ryan House development. Today he remains active with Ryan House on its Founder’s Board, while he adds the role of entrepreneur to his c.v. as well! In addition to her continuing role as Community Liaison for Ryan House, Holly is Vice President of the Arizona Chapter of Families of SMA. Her professional background includes elementary education, early literacy intervention and she is proud to advocate for children with special healthcare needs. The Cottors reside in Scottsdale, Arizona with their 13-year-old son, Ethan, and their now 10-year-old son, Ryan.

JILL KAGAN has served as chair of the National Respite Coalition since 1994. Prior to this she served as staff to the House Select Committee on Children, Youth and Families. Currently, she is Program Director for the AoA funded Lifespan Respite TA Center at the ARCH National Respite Network and Resource Center in collaboration with the Family Caregiver Alliance.
GREG LINK is an Aging Services Program Specialist with the U.S. Administration on Aging. He is the Federal program officer for the National Family Caregiver Support Program and the Lifespan Respite Care Program. In that capacity, he provides general oversight and technical assistance on matters pertaining to the implementation of those programs and other issues associated with HCBS.

GUY G. MIKKELEN has served as the CEO and President of FSL since 1985, and he previously served as Director of the State Block Grants Administration for the Arizona Department of Economic Security. Guy has served on the Catholic Charities USA Commission on Aging. He was the recipient of Bishop McCarthy Life Time Achievement Award for serving the poor. He has also been a member of two task forces appointed by Governor Napolitano - Benefits Check-Up and Work Group on Long Term Care and has supported development of the 2020 State Aging Plan. Guy has an undergraduate degree from Carroll College and a Masters of Social Work from University of Wisconsin Milwaukee. He currently serves as a Board member of CASS, the Arizona Commission on Housing, and the City of Phoenix Human Services Commission.

MELANIE STARNS, MAG, is Assistant Director, Arizona Department of Economic Security, Division of Aging and Adult Services
Melanie Starns serves as the Assistant Director of the Department of Economic Security, Division of Aging & Adult Services. Her division provides a safety net of services to the community, working to ensure safety and self-sufficiency so that all Arizonans can live with dignity and independence throughout their lives. Melanie provides vision and leadership to a myriad of programs and services to reach a diverse population of Arizonans from homeless youth to older adults. Previously she served as Governor Janet Napolitano’s Policy Advisor on Aging and Director of the Governor’s Office on Aging where she lead the state’s Aging 2020 and Arizona Mature Workforce Initiatives and managed Executive Orders on Long Term Care Quality and Health Care Workforce Planning – all efforts designed to help Arizona prepare for a growing aging population.

Originally from Denver, Colorado, Starns holds a Master’s degree in Gerontology from the University of Southern California and a Bachelor’s of Science degree in Social Work from Kansas State University. She enjoys creating jewelry and glass art, collecting rocks and fossils and spending time with her family.

EDWIN WALKER
As the Deputy Assistant Secretary for Program Operations with the Administration on Aging (AoA) within the U.S. Department of Health and Human Services, Edwin L. Walker serves as the chief career official for the federal agency responsible for advocating on behalf of older Americans. For more than 25 years, he has been characterized as a consummate professional civil servant who can be relied upon to represent the best interests of our nation’s senior citizens. Prior to joining the Administration on Aging, Mr. Walker served as the Director of the Missouri Division of Aging, responsible for administering a comprehensive set of human service programs for older persons and adults with disabilities.
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ARIZONA CAREGIVER COALITION

MISSION AND VISION

The mission of the Arizona Caregiver Coalition is to create awareness of caregiving issues and improve the quality of life for caregivers and care recipients through advocacy, information and education, support, and access to resources.

The vision of the Arizona Caregiver Coalition is for all Arizona caregivers to have knowledge of and access to resources that support them.

BENEFITS OF MEMBERSHIP

Membership in the Arizona Caregiver Coalition means having a powerful collective voice to advocate for family caregivers! It means meeting new people that support caregivers, learning new ways to reach and help caregivers, and creating a statewide network to allow caregivers easier access to critical support services like respite and training.

OBJECTIVES

The Arizona Caregiver Coalition, in conjunction with our community partners and members, will work together to achieve the following shared objectives:

- Promote awareness of caregiving and its challenges.
- Strengthen and unite existing resources and information supportive of caregivers and respite care.
- Advocate for caregivers and their families relative to supportive programming.
- Work to improve service delivery and reduce barriers to caregivers receiving supportive services.
- Facilitate the development of a system of easy access to respite care for caregivers.
- Respond to community needs and provide for needs of caregivers now and in the future.
- Improve public and private non-profit collaboration relative to caregiver support and respite care.
- Support strategies and activities related to family caregivers included in the State Plan on Aging.
- Recruit and supervise volunteers to staff a caregiver resource hotline.

www.azcaregiver.org
Learn more about the Conference:

The Many Faces of Respite

14th Annual
National Lifespan Respite
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