Supporting Caregiving Coalitions across the US

January 2009

News from the Alliance:
As the season’s festivities recede, the Alliance has turned its thoughts to what will drive caregiving coalitions to success in this New Year. We are excited about our upcoming and on-going opportunities!

The Alliance will host the 3rd National Conference for Caregiving Coalitions on Wednesday, March 18, as part of the 2009 Aging in America, ASA/NCOA Conference in Las Vegas, NV. At this half-day event, caregiving coalitions will learn about evaluation tools, sustainability, innovative caregiving programs, fundraising, and outreach to caregivers and other organizations. This half-day event is being held in conjunction with the Family Caregiver Alliance, which is hosting a session on state policy issues in the afternoon following our portion on caregiving coalitions. Both sessions are open to everyone and we strongly encourage all caregiving coalitions to attend. For more information, please see the Events and Opportunities section

This month, the Alliance, along with the Centers for Medicare and Medicaid Services (CMS), will host the first 2009 quarterly CMS/NAC Coalition Network conference call on Wednesday, January 14. The call will feature Heather Mahoney-Gleason from the U.S. Veteran’s Administration who will talk about a new VA program that is providing outreach to family caregivers and discuss ways in which some local VA offices in California are working with caregiving coalitions to provide outreach and support. To learn about how to participate in this call, please visit the Alliance/CMS Caregiving Coalition Conference Call section.

This month’s Resources, Reports and Publications section contains links to a number of newly released reports and publications on topics ranging from Family Responsibilities Discrimination to home care in Europe, and the Events and Opportunities section highlights a training opportunity for caregivers of people with Traumatic Brain Injury, Post Traumatic Stress Disorder, or dementia. The Legislative Update includes information on the Retooling the Healthcare Workforce for an Aging America Act, which aims to expand education and training opportunities in geriatrics and long-term care.

As the New Year begins, the Alliance is eager to hear about the plans and goals that your coalition has for 2009, as well as the support, information, and technical assistance that your coalition needs to be successful in 2009. As always, we welcome your input, want to hear about any event your coalition is planning, and appreciate any examples of materials or resources that your coalition develops. If you have stories or materials to share, or if you need information or support, please contact Angelia Bowman at angelia@caregiving.org or (301) 718-8444

Gail Gibson Hunt
CEO and President
National Alliance for Caregiving
Coalition News and Updates

New Jersey: In recognition of November as National Family Caregivers Month, the United Way’s Caregiving Coalition of Morris County hosted a Caregivers Resource Fair, where caregivers found over 50 exhibitors who ready to answer their questions and provide information about services for themselves and their loved ones. Held in the Morris County Public Safety Training Academy, the exhibitors for the event included home health agencies, care managers, benefits specialists, mobility specialists, mental health agencies, independent living centers, nursing homes, elder law attorneys, hospice, and visiting nurse organizations. In addition to receive practical information about services and resources, attendees were also able to receive free massages, blood pressure screenings, benefits consultations, and demonstrations of helpful mobility equipment and devices. Members of the Caregivers Coalition of Morris County greeted caregivers as they arrived at the Resource Fair and provided them with a copy of the Coalition’s Pathways for Caregivers guide. To learn more about the Caregivers Resource Fair, please visit: http://www.uwmorris.org/newsevents/ev_08_caregivers.html

New York: In honor of AARP’s 50th anniversary, AARP New York is recognizing 50 New Yorkers who have been our champions of social change. The chosen awardees have demonstrated an exceptional commitment to enhancing the lives of New Yorkers, improving their communities, and inspiring others in the areas of financial security, health care, livable communities, images of aging, giving back, arts and entertainment, and learning. Greg Johnson, of the New York City Family Caregiver Coalition and a featured presenter at the National Conference for Caregiving Coalitions and the Regional Meeting for Caregiving Coalitions in Los Angeles, is one of the distinguished awardees. To learn more, please visit: http://www.aarp.org/publish/etc/medialib/aarp_media_library/states/new_york.Par.28116.File.dat/NY-AARP%20Honoree%20Bios.pdf

Promising Practices: The Alliance is Seeking Promising and Innovative Practices
The Alliance is developing a database of innovative and promising practices undertaken by caregiving coalitions and organizations. These “promising practices” will: encourage the exchange of ideas and initiatives between caregiving coalitions and organizations about innovative and/or exemplary programs; equip caregiving coalitions and organizations with information and practice ideas that can be used to improve resources and services within their own programs and practices; and, promote quality and innovative programs to the field.

We are interested in hearing about projects in the area(s) of:

- **Respite Initiatives**: providing information, referrals, and advice on respite services.
- **Caring for the Caregiver**: helping caregivers take time for themselves, connect caregivers to support within the community, address caregiver health, etc.
- **Development and Education**: providing education, training, and other resource opportunities to caregivers, health providers and/or other professionals.
- **Single Parent Caregiver Populations**: support to single parent caregivers who are caring for children while also caring for an aging, sick, or disabled family member.
- **Underrepresented Caregiver Populations**: support to minority, rural, veteran, and/or other underrepresented caregiver populations.

If your coalition or organization has been or is involved in a practice or project that is innovative or promising within these topical areas, please send an e-mail to Angelia Bowman at angelia@caregiving.org with your name, organization, city/state/zip code, contact phone, contact
Alliance/CMS Caregiving Coalitions Conference Call

Please join us for the first 2009 quarterly CMS/NAC Coalition Network conference call on Wednesday, January 14 from 1-2 PM EST. The call will feature Heather Mahoney-Gleason from the U.S. Veteran’s Administration who will talk about a new VA program that is providing outreach to family caregivers and discuss ways in which some local VA offices in California are working with caregiving coalitions to provide outreach and support.

Call-in Information
Date: Wednesday, January 14, 2009
Time: 1 to 2 p.m. (Eastern Time)
Toll-free phone number: 1-888-322-3914
Passcode: Caregiver
Call Leader: Cora Tracy, Center for Medicare and Medicaid Services (CMS)

Agenda:
1. Welcome to the Call: Cora Tracy, CMS, and Gail Gibson Hunt, National Alliance for Caregiving (NAC) (5 minutes)
2. Update from the NAC: Gail Gibson Hunt (10 minutes)
3. Update from CMS: Susie Butler, CMS (10 minutes)
4. Legislative Update: Angelia Bowman, NAC (5 minutes)
5. Collaborating with the Veteran’s Administration: Heather Mahoney-Gleason, U.S. Veteran’s Administration (30 minutes, with question and answer period)

Legislative Update

Federal
Retooling the Healthcare Workforce for an Aging America Act (S. 3730): Introduced by Senator Herb Kohl (D-WI) Chairman of the Senate Special Committee on Aging, on December 10, 2008, the Retooling the Healthcare Workforce for an Aging America Act seeks to expand education and training opportunities in geriatrics and long-term care for licensed health professionals, direct care workers and family caregivers in order to better prepare the workforce for meeting the needs of the growing older adult population. The proposed bill permits state Medicaid programs to conduct a family caregiver’s needs assessment and to provide referral to appropriate services when the care recipient is a Medicaid beneficiary who qualifies for home and community-based services and who relies on the family caregiver for much of their care. The bill also ensures that health care providers provide family caregivers of Medicare beneficiaries with information and referral to community support services at the point of discharge from a hospital, skilled nursing facility, or rehabilitation facility. To read a summary of the key points of the bill, please visit: [link]

Resources, Reports and Publications

Boston College has released a research brief for state policy makers which describes state policy efforts to address employment discrimination in which workers are fired, demoted, not promoted, denied employment benefits, or harassed because of their caregiving responsibilities for a child, partner, or older relative. *Addressing Family Responsibilities Discrimination* also details recently proposed family responsibilities discrimination legislation in California, Florida, Iowa, Michigan, New Jersey, New York and Pennsylvania. The brief also explores the growing problem of such discrimination, why it is a policy matter and how it negatively impacts both employees and their employers.

**Full Brief: Addressing Family Responsibilities Discrimination**, Center for WorkLife Law and the Sloan Work and Family Research Network (Boston College),

**Baby Boomers Moving in with Adult Children (U.S. News and World Report):** In November, a *U.S. News and World Report* story discussed a growing trend in parents living with their adult children for financial and cultural reasons, as well as for convenience or caregiving needs. In addition to discussing the needed care for elderly or sick parents that such living arrangements can provide, the article also stresses the need for open communication and respite for caregivers, both of which are essential to making such arrangements successful.

**Full article:** Baby Boomers Moving in with Adult Children, by Emily Brandon of *U.S. News and World Report*, November 20, 2008:

**The Solid Facts: Home Care in Europe (World Health Organization):** The World Health Organization recently released a report called *The Solid Facts: Home Care in Europe*, which examines the importance of high-quality and target home care for older adults and adults with disabilities in the context of changing demographics and the aging of the population in Europe. In addition to detailing the effectiveness of home care, showing how it can be improved, and explaining the need to ensure equitable access, the report also explores how to educate professionals and the public about these issues.


**Autistic Children Require More Money, Time than Children with Other Chronic Diseases** *(Pediatrics):* Children who have autism have health care needs that are both more costly and more time intensive than children with other chronic ailments, according to a Maternal and Child Health Bureau study published in *Pediatrics*. The study, which surveyed nearly 40,000 children with special health care needs between 2005 and 2006, found that parents of children with autism were three times more likely to quit their jobs or reduce their work hours to care for their children than parents of children with other chronic diseases. The study also found that these parents often spend more on care for their children and are more likely to have financial difficulties and spend more time arranging for care.

http://pediatrics.aappublications.org/cgi/content/abstract/122/6/e1149?maxtoshow=&HITS=10 &hits=10&RESULTFORMAT=&fulltext=autistic&searchid=1&FIRSTINDEX=0&volume=122&issue=6&resourcetype=HWCIT
Red Cross Offers Caregiving Guide: The American Red Cross is offering a guide and a DVD to help families deal with the challenges of caring for a loved one who has a long-term illness or limited mobility. *Family Caregiving* is a quick reference guide with a companion DVD designed to assist caregivers by providing the best medical, nutritional and financial care. Among the topics covered are basic caregiving skills, home safety, healthy meal planning, and dealing with financial and legal issues. The guide also includes charts for recording vital signs and medications, as well as an emergency contact card. The DVD includes easy-to-follow demonstrations of first aid for some of the most common emergencies, such as choking, stroke and heart attack. For more information, please visit: [http://www.redcross.org/services/hss/care/family.html](http://www.redcross.org/services/hss/care/family.html)

Acute Care Utilization by Dementia Caregivers (Journal of General Internal Medicine): A recent study, highlighted in the Journal of General Internal Medicine, examined the impact of stress on the physical and mental health of Alzheimer’s caregivers by assessing caregivers for depressive symptoms, emergency department use and hospitalizations. Main findings included that nearly one-fourth (24%) of caregivers had at least one emergency room visit or hospitalization in the previous six months and that the caregivers’ acute care utilization was associated with their level of depression, plus the care recipients’ behavioral and psychological symptoms and their functional status. 

**Full Article:** *Acute Care Utilization by Dementia Caregivers* by Cathy C. Schubert et al in *Journal of General Internal Medicine*, Volume 23, Number 11 (November 2008): [http://www.springerlink.com/content/p457552152000915/?p=7a756e33ecb4443f9fac4f699b81f056&pi=1](http://www.springerlink.com/content/p457552152000915/?p=7a756e33ecb4443f9fac4f699b81f056&pi=1)

AHRQ Preventive Health Guides Now Available in Spanish: As reported in the September 2008 *Caregiving Exchange*, the Agency for Healthcare Research and Quality (AHRQ) recently released a checklist for men and one for women that is founded in evidence-based recommendations from the US Preventive Services Task Force regarding screening tests, prevention medicine, and healthy lifestyle behaviors. These checklists are now available in Spanish. The women’s checklist is available here, [http://www.ahrq.gov/consumer/women50sp.pdf](http://www.ahrq.gov/consumer/women50sp.pdf) (For English: [www.ahrq.gov/ppip/women50.htm](http://www.ahrq.gov/ppip/women50.htm)); and, the men’s checklist is available here, [http://www.ahrq.gov/consumer/men50sp.pdf](http://www.ahrq.gov/consumer/men50sp.pdf) (For English: [www.ahrq.gov/ppip/men50.htm](http://www.ahrq.gov/ppip/men50.htm)) Family caregivers of those 50+ may want to have this checklist to be sure that their loved one is addressing all the necessary healthcare issues. If they are 50+, caregivers themselves should be sure that they are also following the checklist.

Benefits for spouses outweigh caregiving stress (Psychological Science): According to a study to be published in *Psychological Science*, senior citizens who care for their spouses live longer than others. Although previous studies have reported about the stress involved for seniors who must care for a spouse in poor health, this study adds to a growing literature on the positive, beneficial health effects of caregiving. For the study, lead author Stephanie Brown and her colleagues reviewed seven years of data from the University of Michigan Health and Retirement Study, a nationally representative sample of 1,688 American couples age 70 and older.

Quick Links:


**Events and Opportunities**

**Building Better Caregivers Workshop and Study:** The Stanford School of Medicine and the Department of Veterans Affairs, California Offices on Caregiving, are conducting a study testing a new online workshop for caregivers of people with Traumatic Brain Injury (TBI), Post Traumatic Stress Disorder (PTSD), or dementia (Alzheimer's or other dementia). This free 6-week internet class on self-care/self management workshop to benefit veterans and their caregivers is now open for registration to family caregivers of veterans or veterans who serve as caregivers. Eligible participants are in California, Southern Nevada and Hawaii and are providing care for individuals with Traumatic Brain Injury, Post Traumatic Stress Disorder or Dementia. This course covers:

- skills that may lead to stress reduction for the caregiver and veteran
- self-care methods to maintain or enhance health
- dealing with difficult emotions
- managing difficult care recipient behaviors
- planning for the future
- information about VA and community resources
- communications skills to increase effectiveness with both the care recipient and the medical staff
- how to ask for help when you need it

For more information please visit [https://caregivers.stanford.edu/hl/hlMain](https://caregivers.stanford.edu/hl/hlMain). Please feel free to share the attached information to appropriate caregivers and other interested staff or groups. There will be a number of classes with varying start dates, filled on a first come, first serve basis.

**Volunteers needed for a Research Study:** If you are an African-American, American Indian, or Hispanic caregiver, you may qualify to participate for this study to if you have a relative or friend with some memory loss who lives at home and who does not live with you. The purpose of this study is to help other caregivers and health providers to learn more about the important needs of caregiving from a distance. The study researchers are seeking volunteers to share their experiences in a 35-40 minute phone conversation. The phone call will be planned at your convenience and you will be paid for your time. If you or someone you know is a distance caregiver and you wish to learn more about the study,
contact Jane Thomas at the University of Oklahoma Health Sciences Center at 1-877-271-4991 or jane-thomas@ouhsc.edu.

****March 18: 3rd National Conference for Caregiving Coalitions, Las Vegas, NV: Supporting Sustainable Caregiving Coalitions, 8am to 2pm: State and local caregiving coalition members are invited to attend the Third National Conference for Caregiving Coalitions on Wednesday, March 18, 2009 at the Bally’s Hotel in Las Vegas, Nevada as part of the 2009 Aging in America, ASA/NCOA Conference. At this half-day event, caregiving coalitions will learn about evaluation tools, sustainability, innovative caregiving programs, fundraising (grant writing, membership, etc.), and outreach to caregivers and other organizations. The sessions will be designed and led by caregiving coalition leaders who were recruited by the Alliance based on their experience and expertise as coalition leaders. The half-day event will include training in a workshop format and will allow for breakouts and discussion. Lynn Friss Feinberg, who has spent the past year working in Senator Barbara Boxer’s office as the Heinz Fellow, will join us as the keynote speaker to discuss federal policy issues.

This half-day event is being held in conjunction with the Family Caregiver Alliance, which is hosting a session on state policy issues in the afternoon following our portion on caregiving coalitions. Both sessions are open to everyone.

Presenters:
Keynote Speaker: Lynn Friss Feinberg, MSW, Deputy Director, National Center on Caregiving, Family Caregiver Alliance
Sonny Yudell, Program Manager, Utah Division of Aging and Adult Services
Donna Heppermann, MSW, Generations Program Director, Beatitudes Center Developing Older Adult Resources (DOAR), Arizona
Brian Duke, MHA, MBE, Director, Buck’s County Area Agency on Aging
Ellen Nau, Program Coordinator, Virginia Department of Aging

Important Registration Information:
There is no registration fee for the NAC event but you will need to register for the March 15-19 ASA/NCOA conference, which allows you to attend all the workshops, exhibits, and keynote speakers.

If you are already an ASA or NCOA member, you can register for this event through the regular ASA/NCOA registration process. If you are not an ASA or NCOA member, becoming a member will make you eligible for a lower registration rate. The early registration rate for a nonmember is $595.00; the registration rate for a member is $425. The early registration rate for the 2009 ASA/NCOA meeting ends January 23, 2009. To learn more about the conference, please visit: http://www.agingconference.org/asav2/conf/jc/jc09/gen_info2.cfm

If you have any questions please contact Angelia at: 301-718-8444 or angelia@caregiving.org.