News from the Alliance:

Caregiving in the U.S., results from the 2009 National Caregiver Survey was released December 8, 2009. This updated survey will include three companion reports: parents caring for children with disabilities, family caregivers of young adults (age 18-49), and family caregivers of those age 50+.

While the information we gain from this new survey breaks down important demographics on age, race, education levels, income, and cultural distinctions, it also conveys the intensity of caregiving responsibilities, the types of assistance caregivers provide, and identify the unmet needs of caregivers.

This study of the legions of people caring for adults, the elderly and children with special needs reveals that 29% of the U.S. adult population, or 65.7 million people, are caregivers, including 31% of all households. These caregivers provide an average of 20 hours of care per week.

The study also revealed that both caregivers of adults and their care recipients are now older than their counterparts were five years ago. Among caregivers of adults (ages 18 or older), the average age of the caregiver rose from 46 to 49. The change can be attributed to a decline among younger caregivers (those under the age of 50) and a shift upward among caregivers age 50 to 64. Among caregivers of adults, the average care recipient’s age increased from 67 to 69, mainly because of an increase in the percentage age 75 or older (from 43% to 51%).

Caregiving in the U.S., which was funded by MetLife Foundation and conducted for the National Alliance for Caregiving in collaboration with AARP by Mathew Greenwald & Associates, is the result of interviews with 1,480 caregivers chosen at random. The study was designed to replicate similar studies conducted in 2004 and 1997.

The companion reports and entire survey can be found on our website: www.caregiving.org

The National Alliance for Caregiving (NAC) and the National Center on Caregiving (NCC) at Family Caregiver Alliance (FCA) are hosting sessions at the 2010 Aging in America Conference focused on mobilizing family caregivers and caregiving coalitions in a climate dominated by economic downtown, health care reform and an aging population. The sessions will be held Monday, March 15, 2010 at the Hyatt Regency in Chicago from 9:00 a.m.- 4:00 p.m., with a break for lunch at 12:00. For more information, see our Coalition Updates section of the Caregiving Exchange.

Gail Gibson Hunt
President & CEO
National Alliance for Caregiving
Coalition Updates

Fourth Annual Conference for Caregiving Coalitions!

*Have We Turned the Corner? The Economic Downturn and its Impact on Caregiving Coalitions* will be held from 9:00 a.m. – 12:30 p.m. Speakers will discuss the recently released "Survey of the Economic Downturn and its Impact on Family Caregiving" and "Caregiving in the U.S. 2009." Speakers include Gail Hunt of the National Alliance for Caregiving, Brian Duke of the Bucks County Area Agency on Aging, and a panel discussion with members of the Advocacy Task Force discussing advocacy campaigns & activities as well as models for effective coalitions.

U.S. Congresswoman Jan Schakowsky, a leading voice in health care reform and sponsor of the Retooling the Healthcare Workforce for an Aging America Act of 2009, will kick off the day's events with a presentation at 9:45 a.m.

5 Scholarships will be awarded once again this year to the Coalitions. These scholarships will provide up to $850 for travel, hotel and per diem for individual coalition members. To apply for a scholarship, please submit a one-page attachment via email to Jordan Green at Jordan@caregiving.org by February 12, 2010. The one-page attachment should include the name of your coalition, your contact information, and a description of any recent activities around caregiver awareness.

**Important Registration Information:**

Even if you are not an ASA Member, we are able to offer all registrants the ASA Member rate for this conference. Here is how to register with the member rate:

When registrants go to the website to begin registration, [http://www.asaging.org/aia10/registration_attendee.cfm](http://www.asaging.org/aia10/registration_attendee.cfm), they will use Attendee Registration and click on “Register Now”.

At the landing page, they should start at Step 2: Select your member status and provide ASA or NCOA membership information for member rates.

By selecting “Member”, and “Individual” and using this ID in the ASA Member ID box: NACm9Car

This will allow you to register with the discounted member rate. Please note that the ID is case sensitive so type it in exactly as show above

**NYC Family Caregiver Coalition’s** Reverend Gregory L. Johnson, founding member and co-chair, took part in a radio interview with the Longevity Club that is in regard to FAMILY CAREGIVING 101 and those caregivers who are just starting out in their caregiving responsibilities. This is extremely helpful for people who are long distance caregivers, and people who simply need to be able to access information on a schedule that works for them.

To listen to the interview, visit: [www.longevityclubonline.com/radio.htm](http://www.longevityclubonline.com/radio.htm)
To Access the Interview:

- Once you have clicked on the link above, scroll down to the date: November 25, 2009
- Click on Greg Johnson; Emblem Health
- Select Play & send on to a family caregiver

**United Way of Morris County** held an Agenda for Action: Caregiver Recognition Breakfast in November. Rep. Rodney Frelinghuysen was presented the agenda during this breakfast and was the keynote speaker for the event. The agenda seeks more attention paid to caregiver concerns when health care, social or long-term care policies are created; that an affordable, well-qualified health care workforce is available in all care settings; better health care coordination for those with chronic needs; incorporating caregivers into the health care team to promote responsibility between providers, patients and caregivers; the availability of respite care for caregivers; and family-friendly policies in the workplace.

**Hawaii Family Caregiver Awareness Day and Resources Fair**
The Hawaii Family Caregiver Coalition will sponsor the 2010 Family Caregiver Awareness Day and Resources Fair on February 26 at the State Capitol, near the mid-point of the Legislative Session. The awareness day and resource fair has turned into a successful annual event with the purpose ensuring that issues concerning family caregivers have the attention of Legislators and informing Legislators of the bills in the current session which are the priorities of the Coalition. The fair takes place in the corridors along the atrium of the capitol and in conference rooms made available to the Coalition. The event is open to the public but special invitations are issued to Legislators and their staff.

The day includes several kinds of activity: 1) over 40 exhibitors representing providers of services and products to older adults to their family caregivers; 2) the publication and distribution to all Legislators of the *2010 Aging Issues* booklet, which summarizes the legislative issues dealing with aging, caregiving, and long-term care, together with legislative tools (current bills and resolutions) designed to deal with these issues; 3) a luncheon to which legislators and their staff are invited and which includes a brief program; and 4) scheduled visits to key legislators, especially those chairing the relevant committees and serving on the finance committees. These visits focus on the highest priority bills and pair a family caregiver and a member of one of the senior advocacy organizations. The family caregiver can describe their situation and how they would be helped by the proposed measure, and the advocate can provide detailed talking points. We recruit family caregivers from support groups as volunteers to participate in this activity.

Since initiating this event, we believe that the awareness of issues facing older citizens and their caregivers and support for positive policies and programs has significantly increased among our Legislators. We also involve the media in publicizing the Family Caregiver Day and Resource Fair and in reporting the event in order to increase support for measures assisting family caregiving in the broader community.

**An Update from the Central Arizona Kinship Care Coalition**
This has definitely been a year of transition for the Central Arizona Kinship Care Coalition. We have put our new structure in place, and it has become easier to handle the various committees and programs now that we have a set of procedures. There have been successes, but also a few setbacks along the way.
For Grandparent’s Day, several of our partner agencies sponsored ice cream socials for kinship caregivers and children. One agency hosted 150 people! There were games, prizes, a magician, and lots of fun. We had previously offered tickets to a major league baseball game. But, due to funding cuts, member agencies were not able to underwrite the reduced cost of tickets. Our Grandparent University was also scaled back. Instead of an all-day session as we had done in the past, we sponsored a specialized track in a major caregiver conference organized by several local agencies. About 60 grandparents attended a half-day workshop on non-medical strategies for coping with emotional and behavioral issues.

We have lost a few of our members, because their programs have been eliminated. However, other agencies have stepped up to take referral calls and help this important group of caregivers whenever possible. Our advocacy, membership, and education committees continue to function. This has been a difficult year for social services. But, by thinking outside the box, working together, and keeping focused on our goals, we will remain an important resource for the kinship caregivers of Central Arizona.

A Letter from the Utah Coalition for Caregiver Support and Time Banking
The Utah Coalition for Caregiver Support (UCCS) has started a Time Bank!! For those of you who are curious about the time banking concept check out their website: [www.timebanks.org](http://www.timebanks.org) The UCCS’s initial idea was to become a Time Bank and exchange services between coalition members. This did not turn out to be the best idea. Instead, we changed our direction and are now working towards helping other community entities develop Time Banks.

The basic concept in Time Banking is that for every hour you spend doing something for someone in your community, you earn one Time Dollar. Then you have a Time Dollar to spend on having someone do something for you.

There are five core values of Time Banks:

1. Assets: We are all assets. Every human being has something to contribute.
2. Redefining Work: Some work is beyond price. Work has to be redefined to value whatever it takes to raise healthy children, build strong families, revitalize neighborhoods, make democracy work and make the planet sustainable.
3. Reciprocity: “helping” works better as a two-way street.
4. Social Networks: We need each other. People who help each other also reweave supportive, strong and trusting communities through creating networks that will build mutual respect and commitment.
5. Respect: Respect demands accountability. All our voices must be heard and heeded.

There are many steps to take before you are a time bank…but the steps are not difficult and are rewarding when you see how you can increase community cohesiveness and, therefore, increase service to each other.

The UCCS has made its first presentation to residents at a local senior high-rise building. Fifteen residents attended, were interested, smart and asked about the next steps. We planned a second presentation at the same location since many residents who did not attend the presentation were curious and concerned that they “missed something”.


This is an exciting step forward for the UCCS. We believe that by helping to create time banks, we are taking a step toward making a huge difference in our community. Time Bank members can create a circular flow of neighbors taking care of each other as an extended family as well as rely on each other for day-to-day services that will support and strengthen their communities.

If you would like to share information about the creation of your caregiving coalition or other information about your coalition’s activities, please email Jordan Green: Jordan@caregiving.org

Legislative Update

**State Legislatures Convene New Session: Harsh Budget Reality and Tough Choices Ahead:** States are struggling to maintain an array of health programs and payment obligations that cost most states more than 30 percent of state budgets. According to the National Council of State Legislatures (NCSL), economic conditions have forced many states to continue to look at cutting or scaling back programs, increasing taxes, and implementing hiring freezes and furloughs. Most analysts believe that budget cuts will again be deep in 2010. States are heading into an era of retro budgeting, where state spending is receding to levels of five to 10 years ago. For health care expenditures this is particularly painful.

At the same time, the number of people on Medicaid and state spending on the program are climbing sharply as a result of the recession, straining budgets and pressuring officials to cut costs despite increased financial help from the federal government, according to a December 30, 2009 survey by the Kaiser Family Foundation, see [www.kff.org/medicaid/medicaid123009nr.cfm](http://www.kff.org/medicaid/medicaid123009nr.cfm)

**California** Governor Arnold Schwarzenegger is planning a $750 million in cut to Medi-Cal, the state’s Medicaid program, and health care advocates estimate that California budget cuts will have forced more than 450,000 Californians, including those severely disabled people to either pay for, or go without dental care. Home and community-based supports and services will also be impacted for those on the state’s Medi-Cal program. However, the governor is seeking an additional $1.8 billion more in federal Medicaid funds by raising California’s match to the national average of 57 percent.

**Connecticut** passed a law to permit an employee to take up to 26 weeks of unpaid leave to care for an immediate family member or next of kin who is a member of the military, and is undergoing medical treatment, or suffered a serious injury. For additional information, see [www.cga.ct.gov/](http://www.cga.ct.gov/)

**Arkansas** the state will establish an Alzheimer’s disease Task Force composed of a variety of experts along with family caregivers. The committee will assess the needs of Alzheimer’s patients and family caregivers and develop a strategy to respond to the needs of those impacted by the disease.
National

Health Reform
As you may know, the big news of this quarter is healthcare reform. The following is an update as of the first week of January 2010, knowing that legislative developments change quickly.

After the Senate passed *The Patient Protection and Affordable Care Act* on December 24 by a vote of 60-39, the House and Senate Democratic Leadership have begun closed door meetings to merge the two health care bills. They are strongly considering skipping a formal conference process so they can avoid much of the procedural hurdles and send a bill to President Obama as soon as possible, ideally before the State of the Union. If this scenario plays out, the House could pass an amended version of the Senate bill that includes additional compromises added by the House and Senate negotiators, followed by a Senate vote on the same amended bill which would then be sent to the President for signature.

Both the House and Senate Bills have components that will positively impact family caregivers. Both the House and the Senate Bills include a CLASS Act provision, emphasize preventative care and expand flexibility and incentives to access home and community-based services, while only the House bill expands funding for the Family Caregiver Support Program.

To learn more about the various provisions on the House Tri-committee bills, and the Senate HELP Committee bill and the Senate Finance Committee bill, please review the Kaiser Foundation website for an unbiased, easy to use interactive side-by-side analysis that compares the health reform bills. This side-by-side offers a summary of the major components of these proposals; detailed descriptions of provisions relating to the Medicare and Medicaid programs. Visit, [http://www.kff.org/healthreform/sidebyside.cfm](http://www.kff.org/healthreform/sidebyside.cfm)

*House and Senate Health Reform Bill Summary:*
While differing in key details, the House and Senate bills share a basic fiscal premise: extending health insurance coverage to nearly all Americans, and not add to the deficit over the 10-year budget window or beyond. To accomplish this, both bills would pay for the cost of expanding coverage with a mix of spending cuts, penalties and taxes.

**Expanding coverage**
According to CBO estimates, the House bill would expand coverage from 83 percent of the legal nonelderly population in 2010 to 96 percent by 2015. The Senate version would expand such coverage to 94 percent by 2016. This would be achieved by expanding Medicaid, requiring most individuals to obtain coverage or pay a penalty, requiring most employers to provide coverage or pay a penalty, and assisting many individuals and employers with subsidies or tax credits to help defray the costs.

<table>
<thead>
<tr>
<th>House bill:</th>
<th>Senate bill:</th>
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<tr>
<td>Medicaid expansion: $425 billion</td>
<td>Medicaid expansion: $395 billion</td>
</tr>
<tr>
<td>Premium subsidies: $602 billion</td>
<td>Premium subsidies: $436 billion</td>
</tr>
<tr>
<td>Employer tax credits: $25 billion</td>
<td>Employer tax credits: $40 billion</td>
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<tr>
<td>Total: $1.052 trillion</td>
<td>Total: $871 billion</td>
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It may appear from the gross cost that the House bill is much more “expensive” than the Senate bill. However, the apparent difference is largely a matter of timing. In the House bill, expanded coverage takes effect in 2013 but in the Senate bill it does not take effect until 2014. Once the two plans are fully
The Caregiving Exchange

January 2010

operational, the cost difference is slight, according to CBO. Gross cost of coverage expansion in 2019:
House bill: $207 billion; Senate bill: $199 billion

Paying for Health Reform
Both bills include substantial spending reductions from the current 10-year baseline. The largest spending
reductions come from changes in Medicare. Both bills would permanently reduce Medicare’s annual
payment updates for provider services other than physicians. They would also reduce payments to
Medicare Advantage plans (Part C) -- private plans that are currently reimbursed at a higher per-capita
rate on average than the traditional fee-for-service Medicare program in return for additional benefits,
lower premiums or both. These two provisions total $398 billion of savings in the House bill and $304
billion in the Senate bill. Other changes in Medicare, Medicaid and the State Children’s Health Insurance
Program (SCHIP) account for the remaining spending cuts.

Both plans would partially offset the cost of coverage by imposing penalties on individuals who fail to
obtain coverage and employers who fail to offer coverage to their employees. These penalties vary
between the two bills but do not constitute a significant source of funding. Their main purpose is to
provide an incentive for individuals to obtain coverage and for employers to offer coverage to their
workers. Both bills also include tax increases. The main revenue raiser in the House bill is a surtax of 5.4
percent on individuals with incomes in excess of $500,000 and couples with incomes in excess of $1
million. This would raise revenues by $460 billion over 10 years.

The Senate’s approach is more diverse, imposing a 40 percent excise tax on high-cost insurance plans
(defined as those with annual premiums of $8,500 for individuals and $23,000 for families), an increase
of 0.9 percent in the Medicare payroll tax for upper income earners ($200,000 for individuals; $250,000
for families) and various taxes on providers.

The bottom line:
The Congressional Budget Office (CBO) has determined that either bill, if enacted and maintained as
written, would slightly decrease the deficit in the 10-year window.

Senate Passes Veterans and Caregiver Support Bill
Wednesday, November 19, after much deliberation and continued closed door negotiation, the Senate
passed S. 1963, the Caregivers and Veterans Omnibus Health Services Act of 2009 in the evening by a
voice vote of 98-0. No changes were made to the bill prior to its passage. The bill has been referred to
the House Committee on Veterans Affairs. We do not expect action until 2010.

Next Step: The bill goes to the House Committee on Veterans Affairs. If passed in the House, depending
on the differences in the House and Senate bills, there could be a conference committee to fix those
differences. Then a vote would be held by both House and Senate again and signed by the President
before it can be in acted into law.

Highlights of the measure: The bill merges two omnibus veterans' health bills, S.801 and S. 252 which
passed the committee in September with bipartisan support. One of the key benefits in the measure is
caregiver assistance for the nation's most seriously wounded veterans who were injured after September
11, 2001. The bill also contains provisions to improve access to care for veterans in rural areas by
increasing access to telecommunications with the VA doctors and specialists, and by establishing Centers
of Excellence in a number of rural areas. This includes a monthly stipend for caregivers of veterans,
travel benefits for family members, caregiver education, training and counseling, extended benefits during
caregiver training, oversight, respite care services, medical care for veterans’ caregivers and provide a survey to family caregivers.

Veterans' Administration Opposition: The VA has expressed opposition to many elements of this bill. They cite soaring program costs -- $62.5 billion over 10 years; sweeping changes in the role of the VA by permitting family members of veterans to access medical care and mental health services from the VA; and creating a new class of benefits for one group of veterans over another. At this time, the Administration has not indicated its support or opposition to the legislation.

CBO Cost Estimate: The CBO believes that these provisions would cost $5.6 billion in FY 2010, $26.8 billion in FY 2011, and $62.5 billion over 10 years. For more information, see, http://thomas.loc.gov/cgi-bin/cpquery/T?&report=sr080&dbname=111&.

If you would like to share information on legislation in your state, please contact Jordan Green: Jordan@caregiving.org

News, Reports and Publications

Family Caregiver Alliance has developed a paper intended to help advocate for state programs, Caregiver Support Programs: Talking Points for Advocates, Administrators, Providers and Caregivers was developed to establish ways to fight for state and local caregiver support programs.

States are currently struggling with one of the deepest recessions on record. As a result, funding for essential services has been reduced or, in the worst cases, eliminated; the most vulnerable people in society have been forced to survive on even less; and social service providers have had to fight for the survival of their programs and agencies.

Services for family caregivers are no exception. Across the country, budgets for publicly funded caregiver support programs are among those not only reduced, but threatened with further cuts or elimination as state revenues continue to drop. These cuts could undo years of hard work establishing programs that focus on the health and well-being of family caregivers and their capacity to provide quality long-term care to their loved ones.

To view the entire paper, visit: http://caregiver.org/caregiver/jsp/content/pdfs/2009-Primer%20State%20Advocacy.pdf

National Senior Citizens Law Center has published an issue brief providing an overview of the boundaries of a state’s Medicaid home health service standard in order to provide useful background for advocates trying to maximize the community-based options of persons with chronic needs. This issue brief, To be or not to be Homebound: The Limits of States’ Discretion in Medicaid’s Coverage for Home Health Services, can be viewed online at: http://www.nsclc.org/areas/medicaid/to-be-or-not-to-be-homebound-the-limits-of-states2019-discretion-in-medicaid2019s-coverage-for-home-health-services/at_download/attachment
The Joint Commission’s latest Speak up Campaign has developed a brochure: How Patients Can Make the Most of a Visit to the Doctor. “A visit to the doctor’s office can be an overwhelming and confusing experience for patients and families,” says Mark R. Chassin, M.D., M.P.P., M.P.H., president, The Joint Commission. “Whether seeing the doctor for a routine checkup or for a specific condition, being informed and involved will help patients and their doctor get the most out of the visit. With knowledge and action, patients can take steps to make sure they receive the best care possible.”

“Tips for Your Doctor’s Visit” advise patients on such important issues as:

- Information to write down and share with the doctor.
- What to do if the patient does not understand the doctor.
- What to ask if a doctor prescribes new medicine.

The Joint Commission’s new education campaign is part of the award-winning Speak Up™ program which urges patients to take an active role in their own health care. Speak Up™ brochures are available in English and Spanish at [http://www.jointcommission.org/PatientSafety/SpeakUp/](http://www.jointcommission.org/PatientSafety/SpeakUp/).

For more information contact, Ken Powers, Media Relations Manager: kpowers@jointcommission.org

**Resources, Events and Opportunities**

**Caring for a Depressed Elderly Parent Podcast** is available for downloading. This podcast features Moderator Neil Johnson and Julie Totten, president and Founder of Families for Depression Awareness, Gail Hunt, President and CEO of the National Alliance for Caregiving, and Jane Richardson who is a caregiver to her 78 year old mother who has bipolar disorder.

Among other topics, the podcast covers:

- The fact that while depression is not a normal part of aging; fifteen percent of the elderly suffer from it. That’s twice as high as the general population.
- Elder care national telephone line (Eldercare Locator: 1-800-677-1116)
- The typical day of a caregiver
- Challenges for the caregiver
- Caregiver support

One important point the podcast emphasizes is that family caregivers themselves are at serious risk for exhibiting depression symptoms. The podcast provides resources for caregivers and family members of caregivers. If you’re a caregiver or have an elderly parent with depression, you’ll find this podcast essential.

**Caring for a Depressed Parent podcast**
Helping an Older Adult Who is Depressed tip sheet

Article about the Caring for a Depressed Elderly Parent podcast

The C.A.R.E. (Cancer Advocate Resources and Education) Campaign is a national program that provides free resources, education and support for those supporting a loved one with breast cancer. One feature of the C.A.R.E. Campaign is a new educational booklet, Frankly Speaking About Cancer: When a Woman You Care About has Breast Cancer. This booklet provides personal stories, checklists and practical advice for caregivers to help them address both their own needs and those of their loved ones. The booklets are available free of charge. To order a booklet, contact: regan@thewellnesscommunity.org

Community Health Ministry is a 501 c3 non-profit rural indigent clinic. They are serving the needs of the uninsured and underinsured population. They agency addresses the whole person. They also distribute food, medical equipment, medication and have professionals that see dental mental and medical care clients. The Community Health Ministry serves over 5,000 users yearly with 7,000 visits. Rosemary Helms R.N. and Lorena Carlson are co-founders of this project. Community Health Ministry also ships medical supplies and other items to over 18 foreign countries. For more information or to help with shipping needs, please contact Rosemary Helms: wchm1@wamego.net

Alzheimer’s Action Day is taking place in Sacramento, CA on April 21, 2010. An Alzheimer’s Task force has been appointed, and three key subcommittees have been identified:

- Care in the Home, Community and Residential Settings
- Medical Diagnosis and Treatment, Health Care Services and Scientific Research
- Public Awareness, Professional Training and Consumer Education

For more information, contact Ruth Gay: ruth.gay@alz.org

Ask Medicare has a new video and resource guide featured on the website: www.medicare.gov/caregivers. The video tells one family’s story, and highlights programs and resources that benefit and enhance a caregiver’s well-being. In addition, the video and resource guide provide links to services available for caregivers and care recipients through the HHS Administration on Aging, HHS Centers for Medicare & Medicaid Services and other state and local programs. To view the video and download the resource guide, go to the Ask Medicare site and scroll to the bottom of the page. This website also allows family caregivers to help a friend or family member choose a drug plan, compare nursing homes, get help with billing, find local resources and more.

If you would like to share information about the creation of your caregiving coalition or other information about your coalition’s activities, please email Jordan Green: Jordan@caregiving.org