



The Caregiving Exchange

Supporting Caregiving Coalitions Across the US

Summer 2007

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News from the Alliance

It is hard to believe that the Alliance is more than halfway through our one-year Caregiving Coalitions project! We are excited and energized by the efforts happening with caregiving coalitions around the country.

As we continue our work to support the 20 coalitions participating in the project, we want to be sure that each group is getting the support it needs to meet the outcomes spelled out in the original project. We have already held 2 webcasts devoted to skills and information-building for coalitions. Two more webcasts are scheduled for August 20 and September 21. We also have continued hosting our joint NAC/Center for Medicare and Medicaid Services (CMS) conference calls (sponsored by CMS) for caregiving coalitions to keep individuals and coalitions informed about important issues across the country. The most recent call featured an excellent interview with Mary Brintnall-Peterson with the Wisconsin Alliance for Family Caregivers.

Now everyone should be gearing up for their November Caregiving Awareness Day activities. November will be here before we know it. That means that planning for Caregiver Awareness Days should be well underway in your community. If you're a little behind the planning curve, don't fret! You can still host a great Caregiver Awareness Day if you begin now.

In coming newsletters, we will outline suggested calendar items for coalition Caregiver Awareness Day planning. This new coalition newsletter format will include information and tips on things like coalition sustainability, advocacy capacity-building, media successes and tools, as well as ideas on how to strengthen your coalition locally. We welcome your input, so if you have suggestions based on previous experience with events such as this, please feel free to let us know so that we can share the information with others.

We look forward to helping you improve upon your event planning and coalition future! If you have an idea about what kinds of things we can do to help make your planning and activities better, let us know. Be sure to stay in touch with NAC staff to help you stay on track, and provide you with the tools you need. Contact Dee Dee Eberle at deedee@caregiving.org, or at (913) 704-8144 if you need information or support. Keep on the lookout for continued tools and information to help coalitions reach as many caregivers as possible!

Gail Gibson Hunt
President and CEO

Coalition News

Exciting news from Eldercare Partners in Minnesota!

Senator Charles Schumer, Joint Economic Committee Chairman, invited Minnesota Senator Amy Klobuchar to hold a hearing on a topic of her choice. Eldercare Partners was delighted to learn that she chose eldercare issues.

Senator Klobuchar requested that Eldercare Partners provide testimony on the impact of elder caregiving before the Joint Economic Committee. The hearing was held May 16th, at 9:30 a.m. The full transcript, as well as a video of the full hearing, can be viewed at <http://www.jec.senate.gov/hearings.htm#051607>. Eldercare Partners was represented by Leni Wilcox, with additional testimony from the Urban Institute, General Mills (employer perspective), and author Virginia Morris.

Eldercare Partners' help was sought by the Senator's office to assemble a roundtable of caregivers to talk with her in Minnesota in February. She turned to this community coalition in large part because Eldercare Partners had received a 2006 Family Caregiving Award from the Alliance and MetLife Foundation, and the opportunity to testify came as a result of that successful roundtable.

To learn more about their experience, contact Beth Wiggins, Vice President of Community Services, DARTS, at beth.wiggins@darts1.org, or at 651-455-1560.

Next Caregiving Coalitions Webcast

The next Caregiving Coalitions Webcast is currently scheduled for Monday, **August 20, 2007**, at **1 pm ET**. These webcasts are held specifically for the 20 coalitions participating in our coalitions project; however, information from these webcasts is available at <http://caregiving.org/coalition/#webcast>. We hope you will log on to utilize the wealth of information provided by our distinguished presenters.

Legislative Update

Alzheimer's Breakthrough Act of 2007

The Senate's Health, Education, Labor and Pensions (HELP) Committee has approved The Alzheimer's Breakthrough Act of 2007 (S. 898). Co-sponsored by Senator Kit Bond (R-MO) and Senator Barbara Mikulski (D-MD), the Act takes a significant step in providing real relief for patients and families suffering from Alzheimer's disease. The Act doubles funding for Alzheimer's research at the National Institutes of Health from \$640 million to \$1.3 billion and will create a national summit on Alzheimer's to look at the most promising breakthroughs. The bill also creates a system for caregiver support that provides updated news, resources and tools for caregivers, families and physicians. The bill now goes to the Senate floor for a vote, which has not yet been scheduled.

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Support for Injured Servicemembers Act

On August 3, 2007, the Senate unanimously approved an amendment extending Family and Medical Leave Act (FMLA) leave for up to six months for the families of wounded servicemembers. The amendment, offered by Senators Dodd and Clinton, had bipartisan support. The measure, titled the *Support for Injured Servicemembers Act*, was included as an amendment to the State Children's Health Insurance Program (SCHIP) reauthorization bill, which passed with a veto-proof majority (68-31). The House passed its own version of the SCHIP reauthorization bill, which will be reconciled with the Senate's version. The House version does not include the *Support for Injured Servicemembers Act*.

Lifespan Respite Care Act

The FY 08 Labor, HHS, Education Appropriations bill includes \$10 million for the Lifespan Respite Care Act, thanks to an amendment offered by Reps. Ferguson (r-NJ) and Langevin (D-RI). The Senate companion bill has no funding for Lifespan Respite and is not expected to come to the Senate floor for a vote until September. Advocates are urged to contact your US Representative and US Senators and urge them to retain the \$10 million for Lifespan Respite Care in the FY08 Labor, HHS, Education Appropriations bill.

To identify your federal legislators and their contact information, visit www.congress.org and enter your zip code. You can send an email or fax containing the message below. The most effective way is to visit them when they are home during the August Recess -- Make an appointment today. Or call them directly. Call the Capitol Switchboard at 202-224-3121 and ask for the Member's office. Then ask for staff who handle appropriations or health issues. For more information, including House and Senate letters signed by over forty Members of the US House of Representatives and US Senate asking Congressional appropriators for Lifespan Funds, visit www.archrespice.org/NRC.htm

Resources

Lobbying And Advocacy

Lobby? Us? You bet! Many times organizations fall prey to a nonprofit myth—that nonprofits cannot lobby. If your coalition is a 501(c)(3) organization, the IRS has guidelines that not only allow you to lobby and advocate, they encourage it! For resources on nonprofit lobbying, check out <http://www.clpi.org>. They have great information for nonprofits that spell out the do's and don'ts, as well as steps you can take as a coalition to support specific legislation and issues in your community and state.

For information and guidance on your state's lobbying laws as they pertain to non-profit entities, check out The National Council of Nonprofit Associations' website at <http://www.ncna.org/index.cfm?fuseaction=Page.viewPage&pageId=624>

Increasing Coalition Membership

Who Cares? Many times, finding new groups or individuals to help sustain membership in your coalition can be a challenge. You've invited or involved all of the "usual suspects" in the caregiving realm, but what about those "unusual suspects"? Has your coalition looked outside the invisible boundaries of who

you think cares about caregivers? Ask current members of your coalition who else in your community would care about caregivers in similar ways.

One community that appears to be under-represented in many of our caregiving coalitions is the disability community. This is a community that is usually:

- Cohesive
- Active in advocacy
- Connected to different types of caregivers
- Eager to work with others on common issues

This community can be a wealth of knowledge and resources in your community, as well as help your coalitions broaden the scope of caregivers you serve.

While not an exhaustive list, below is a list of disability organizations that may have a presence in your community. Reaching out to these groups just might help bolster your coalition's membership in your community.

<i>The Arc</i>	www.thearc.org
<i>Assn of University Centers on Disability</i>	www.aucd.org
<i>Autism Society of America</i>	www.autism-society.org
<i>Brain Injury Association</i>	www.biausa.org/stateoffices.htm
<i>Easter Seals</i>	www.easterseals.com
<i>Independent Living Centers</i>	www.ilru.org/html/publications/directory/index.html
<i>National Down Syndrome Society</i>	www.ndss.org
<i>National Multiple Sclerosis Society</i>	www.nationalmssociety.org
<i>United Cerebral Palsy</i>	www.ucp.org

Media Tools

As we near November's Caregiver Awareness Day events, we need to be sure that we make the most of media opportunities. Building relationships with local media outlets NOW is an important step in ensuring good press coverage of your event, as well as the future efforts of your coalition. Visit our new Coalitions page on our website to see some simple things you can do to start working with the media today. <http://www.caregiving.org/coalition/>

Caregiver Awareness Day Planning Calendar

How are your plans coming? If you're still trying to get things started, or are not sure how to begin planning for your coalition's Caregiver Awareness Day, check out the sample calendar of activities on page 5 to help you get moving.

The sample planning calendar is being used by the Larimer County Caregiver Coalition in Colorado. While it may not list exact dates, it gives this coalition a framework for the efforts they need to undertake to ensure a successful Caregiver Awareness Day event.

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Sample Timeline of Planning Activities

Action Step	Timeframe	Who is Responsible
First planning meeting – divide up tasks	1 st week in July	Core partners – OOA, Alz, Hospice, VOA
Secure Pamper'ers	July – August	Partners
Develop invitation flyer	August/September	OOA / Hospice
Determine caregiver mailing lists	August/September	Partners
Secure Caterer	July	OOA
Mail invitations to caregivers	September (end)	Partners
Secure donations from local businesses	September	CSU Students
Send out volunteer confirmation letters	September (end)	OOA
Collect registrations and pampering choices	October	OOA
Contact media for coverage	October	Alzheimer's Association
Develop personalized caregiver schedules	October	OOA
Send 2 nd letter to volunteers with final details	October	OOA
Send confirmation letter to caregivers	October	OOA
Coordinate with student volunteers	October (end)	CSU Center on Aging
Final coordination with all volunteers	October (end)	Partners
Set up room	Friday, Nov. 2 nd	Partners, volunteers
Hold Caregiver Pampering Day	Saturday, Nov. 3 rd	Everyone
Thank-you letters	November	OOA
Final Evaluation meeting	December	Partners