



The Caregiving Exchange

Supporting Caregiving Coalitions Across the US

September 2007

In This Issue

- News from the Alliance
- Coalition News
- Advocacy Tips
- Next Caregiving Coalitions Webcast
- Legislative Update—August Recess Results
- Reports and Publications
- Resources

News from the Alliance

Beyond November...

As coalitions across the country continue preparations for November's Caregiver Awareness Day activities, the question raised is "what are we doing all of this for?" Of course, coalitions are working hard to bring attention and awareness to the issues of caregiving in local communities. But what, beyond "raising awareness," do we want for the caregivers we serve? How will we know that our efforts are effective in reaching our stated goals?

Everyone's hope is that their efforts have an enduring impact for caregivers in their community. However, it is important to engage in some specific planning to ensure that the long term effects of our activities this November and beyond have a deep and meaningful impact on caregivers.

In coming communications, we at the NAC will be asking coalitions to start thinking about that long-term effect and how coalitions can begin to plan for those enduring impacts. Tools and resources will be available on how groups can start this process in a way that will help ensure sustainability and continuity in the impact we have on caregivers.

If your coalition already has a long-range plan for future efforts and impact, we'd love to hear how you've done it. What has worked? What has created problems? How has your coalition's vision planning helped your short-term activities? Are there tools you've used that you've found useful? Please share your experiences with us so that other coalitions can learn from your valuable insight. Any tips you have for others can be passed along to Dee Dee Eberle at deedee@caregiving.org.

We look forward to your upcoming Caregiver Awareness Day events, and hope that we can help you in your planning and evaluation of those events!

Gail Gibson Hunt
President and CEO

Coalition News

Learning from Others

Through the NAC Caregiving Coalitions project, we are developing a database of the varied plans for Caregiver Awareness events in November. We want coalitions to be able to learn from what others are doing, or have done, to make events successful in their communities. During the last webcast on August 20, coalitions expressed an interest in learning what others were doing for their Caregiver Awareness Day activities. As a result, we disseminated a matrix of the coalitions' plans by email. If you have other resources you would like to share with the coalitions, please send them to us and we will pass them along.

Evaluating Your Efforts

EVALUATION.... The word is tossed about frequently. From a programmatic perspective, we know it is important to "evaluate" the services we provide. But the process can be intimidating, leaving some to easily rationalize that a "real" evaluation may be beyond the scope of a program's resources. As a result, a "good" program can be undermined by an evaluation limited to anecdotal reports or inadequate survey methods that generate information of questionable value to the program.

Despite reservations one may have about evaluation, it is important to recognize it as an essential programmatic tool but it is also a process that we may engage in without realizing we are "evaluating." The methods employed to collect information for evaluation purposes may be many of the same used to monitor program progress on a day-to-day basis – telephone discussions with key stakeholders, debriefings with staff, exit interviews with or surveys of participants, to name a few. Unfortunately, we do not think of these efforts as evaluation because they are not conducted systematically or as part of a plan.

Evaluation should be a process that is helpful and it should be conducted systematically. It should NOT be discussed as you draw near to completion of a program or project. Ideally, you should start planning your evaluation at the beginning of the project. It starts with critical questions. What are you trying to accomplish? How will you know you have achieved it? Is the program being implemented the way it was designed? How will you monitor how the program is being conducted? Which sources of information will you need to address these questions?

These questions will help guide the plan for evaluating progress, providing feedback and measuring impact on the population being served. While participant surveys are a common strategy for evaluating programs, evaluation methods should include multiple strategies that produce different types of information. There are a number of resources available to help you design your evaluation, but it is important that you begin by deciding what information is going to be most helpful to the program and your organization's ability to keep that program going. While it is important to know that "we do a good job," it is as important to identify what needs to be "tweaked" and what needs to be eliminated. These lessons learned can help us to identify priority areas that will strengthen our programs, help us to direct resources more efficiently and offer critical information to plan "next steps."

Future issues of the newsletter will contain more information about how you can effectively evaluate your efforts. If you have an experience with evaluation that you would like to share with other coalitions, please contact us at deedee@caregiving.org.

Advocacy Tips

Election 2008

It's hard to believe that the 2008 election is only a year away. Candidates from all parties are already hard at work trying to garner support in early primary states. The issues we see discussed in the media are as different as the candidates themselves—the War in Iraq, Education, Social Security, Legislator Ethics—take your pick. But how can advocates have a say in what candidates discuss? How can caregiver needs become important top-tier issues with candidates that want our support?

In last month's newsletter, we presented information on how nonprofit entities can—and should—be involved in advocacy. While nonprofits cannot take a position on individual candidates or political parties, they can educate voters about the issues important to caregivers.

One way that coalitions can be involved in raising issues within the framework of ongoing election activities is to get involved in voter education campaigns, or *Get Out The Vote (GOTV)* activities. Here are some basic things that coalitions can consider devoting some effort toward:

- Distributing a fact sheet on issues voters should be asking candidates about (i.e. where do they stand on long term care, respite funding, or kinship care/laws?)
- Providing a list of polling places for primary and general elections, complete with the coalition's contact information on the list
- Registering caregivers to vote
- Helping coordinate transportation to town hall meetings and polling places.
- Attending town hall meetings and asking candidates “What will you do for family caregivers, if elected?”

Candidates need to know what is important to caregivers, and we should be the ones getting people who understand those issues most to the polls on election day. The more caregivers and coalition partners know about the issues important to those we serve, the more impact we can have on the overall political process.

For more information on how you can host a voter registration drive, contact your local League of Women Voters. Find your local contact at

http://www.lwv.org/AM/Template.cfm?Section=Find_a_Local_League

Next Caregiving Coalitions Webcast

The next webcast for coalitions participating in the NAC Caregiving Coalition Project is scheduled for Friday, September 21st at 1:00pm ET. The topic will be “Motivation and Momentum,” addressing how to keep your current members motivated and how to recruit energetic new volunteers to the coalition. Brian Duke will be the presenter. To view the slides and hear transcripts from previous webcasts, please go to www.caregiving.org/coalition/#webcast.

Legislative Update

Wilmington, DE, Coalition Meets With Legislator During August Recess

During the August recess, Susan Getman, Wilmington (DE) Senior Center, and Carolyn Fredricks, Modern Maturity Center, met with U.S. Senator Tom Carper to share important legislative priorities. They discussed concerns shared with many other caregiving coalitions, and were able to provide the Senator with concrete examples of real life seniors who are suffering or in need because important legislation has not yet been passed.

The Senator gave the group a report on some priority issues being debated in Washington, including:

1. Older Americans Act - Sen. Carper understands that additional funding is needed. He asked an aide to follow up on the specific increases noted by advocates prior to the budget coming to the floor for a vote. The threat of presidential veto is very real, however, and requires careful attention by advocates.
2. Improvements in Low Income Seniors and Medicare Enrollment Services - Sen. Carper agreed to have his office investigate the possibility of co-sponsoring S. 1102 and S. 1108. One of his key aides will talk with staff members of the primary co-sponsors and members of the Senate Finance Committee to move this legislation forward. The Senate did not include Medicare issues in its health coverage bill for children from low-income families as the House did because they believe they should be addressed in separate bills.

Sen. Carper also directed his aide to involve constituent services staff in researching what possible assistance is available for people now falling through the cracks in the system. This research will include making contact with pharmaceutical firms to assure that information about their assistance programs is accessible.

3. Lifespan Respite Care Act and The Alzheimer's Breakthrough Act - Sen. Carper is a co-sponsor of both these bills. With his staff's assistance, he agreed to work on getting additional co-sponsors and developing a game plan with other Senate staff members to help get this legislation passed. He wasn't sure how much bipartisan support there is for these bills or if the president will approve, but he is committed to working for it.

Sen. Carper agreed that the meeting was quite useful and proposed that several times each year constituent groups should meet with his staff through conference calls and in person. Because the Delaware congressional delegation works so closely together, he thinks that staff members from Sen. Biden and Rep. Castle's office should participate in these meetings, as well, in order to maximize the effectiveness of the coalition's advocacy. Sen. Carper also urged advocates to ask for meetings with Sen. Biden and Rep. Castle.

Kudos to Susan and the Wilmington Caring Partners Coalition on their continued advocacy efforts!

Reports and Publications

The National Association of Area Agencies on Aging (n4a) published a document entitled *Promising Practices: Engaging Physicians...Supporting Family Caregivers* (September 2004). This publication was designed to help Area Agencies on Aging (AAAs) share their success stories about an innovative physician outreach program called *Making the Link: Connecting Caregivers with Services through Physicians*.

Making the Link was launched in 2002 by n4a with funding from the U.S. Administration on Aging to tap a hidden resource – the physician and his or her staff – for referring family caregivers to aging network services. *Making the Link* provides AAAs and Title VI programs with a comprehensive strategy for engaging physicians in identifying and assisting their patients who are caregivers. It is being implemented in communities across the country by more than 200 agencies. The work of these agencies is complemented by a national awareness campaign involving more than a dozen national medical and caregiving organizations in raising awareness among physicians and the general public about caregiving issues and aging network services.

CMS is currently exploring next steps and what more can be accomplished based on *Making the Link*. To download the publication, go to http://www.n4a.org/pdf/Promising_Practices.pdf.

Resources

Kinship Care Legal Resource Center

Kinship care often raises legal questions for relative caregivers. The American Bar Association Center on Children and Law has launched the Kinship Care Legal Resource Center. The online toolkit provides information and resources on a variety of topics including:

- Statutory preferences for relative placement
- Financial assistance for kinship care providers
- State policies on medical and educational consent

The toolkit can be located at: <http://www.abanet.org/child/>.

Satellite Broadcast on Supporting Caregivers

On Wednesday, September 19, from 1:00 to 3:30 pm (ET), the New Freedom Initiative (NFI) Subcommittee on Caregiving will present a broadcast designed to bring awareness to the range of programs and services the Department of Health and Human Services offers that support caregivers across the lifespan. NFI is a government-wide effort to eliminate the barriers that prevent people with disabilities from participating in community life. A panel of experts will provide information about these programs to increase knowledge of partners and providers, and improve service delivery for caregiving Americans. For participant registration, please go to <http://www.cms.hhs.gov/apps/events/event.asp?id=378>. Please see the National Caregiver Satellite Broadcast page for information on Downlink site registration and viewing, and other items at http://www.cms.hhs.gov/Partnerships/20_CaregiverBroadcast.asp. If you have any questions, please e-mail caregivers@cms.hhs.gov.