



NATIONAL FAMILY CAREGIVERS ASSOCIATION

It Doesn't Have to Be This Hard

The Power of One to Organize Many

An NFCA Commentary 4/07

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has.

Margaret Mead

On the very last day of the 109th Congress (December 8, 2006), family caregivers won a great victory: A five-year effort to gain passage of the Lifespan Respite Care Act came to a happy — albeit nail biting and, to some, a surprise — conclusion, with a voice vote in the Senate. Two days prior, on December 6, the same bill was passed in the House of Representatives. On December 21, It was signed into law by President Bush.

This effort was spearheaded by Jill Kagan, of the National Respite Coalition, a small organization with limited funds. Jill was passionate about her work and had an in-depth understanding of the political process having spent most of her 25-year career as deputy director of a congressional committee (10 years), head of a national advocacy organization, and as a policy consultant to other national and state organizations.

Armed with her passion and experience, Jill pulled together a core group of about 40 diverse organizations, including the National Family Caregivers Association (NFCA), in January 2001. The first meeting was held in an overcrowded conference room at the Easter Seals Washington, D.C., office. There were representatives from the disability community, the aging network, various disease groups, and caregiver organizations. On the phone were the head of the Oregon Respite Care Program, which had been in operation since 1997, and state Sen. Dennis Byars, a member of the Nebraska Legislature, who shared with the group their experiences getting lifespan respite care legislation passed in their respective states.

All family caregivers crave respite. When asked what they need, the answer given most often is: “Time for myself.” Finding that time is never easy: It’s too expensive, the providers are not well-trained, caregivers feel guilty about wanting to get away, the waiting list for public programs is very long, and the list goes on.

Lifespan respite programs are designed to break down those barriers. They pull together all the diverse funding sources for respite that exist in their state because the value of the total pool really is worth more than the sum of its parts. The pool of funding creates far more flexibility in meeting the needs of individual family caregivers. They provide “one-stop” shopping for entry into the system; yet they function on the community level. They train respite workers, both paid and volunteer. They bring together an array of community groups and family caregivers to guide their activities and provide diverse services. They raise the public consciousness about the need

for respite for caregiving families, and, when possible, provide critical funding sources for family caregivers who don't qualify for any other respite program.

Now with the passage of the federal Lifespan Respite Care Act, many more states will have the opportunity to develop programs for their citizens. It wasn't easy getting this far, and the fight isn't over yet. Once a bill is passed, the money to fund it has to be appropriated by Congress — an effort that is going on now.

Helping Jill now, as before, are NFCA, Easter Seals, the Alzheimer's Association, the National Multiple Sclerosis Society, and over 175 national, state, and local groups and their incredible memberships. I'm proud to say that whenever Jill has asked for grassroots support, NFCA members have joined with thousands of other family caregivers and respite supporters across the country to send e-mails and make phone calls to let legislators know the importance of respite.

Jill Kagan's efforts to expand respite opportunities for family caregivers are a very real example of how to use public policy to affect the day-to-day lives of family caregivers. What Jill's work proves is that one person — working tirelessly, pulling together a team, finding ways through the maze of politics to build a path to consensus, creating a sense of urgency, harnessing support from Republicans and Democrats, and keeping the momentum going even when the outcome looked bleakest — really can change the world.

As of this writing there are four states with respite care programs and several others that are making great progress on getting legislation passed. (See the winter 2007 issue of *TAKE CARE!* for a profile of CCAN volunteer Bonnie Danowski of Arizona and her efforts in this area.) Hopefully, your state won't be far behind.

For more information on the Lifespan Respite Care Act of 2006 (H.R.3248.ENR), go to <http://www.thomas.gov/home/multicongress/multicongress.html> and fill in: Lifespan Respite Care Act. Then click on "109th Congress," "Enrolled Bills Sent to the President," "Both House and Senate."

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