



NATIONAL FAMILY CAREGIVERS ASSOCIATION

## “It Doesn’t Have to Be This Hard”

### Do You Live in a Family Caregiver Friendly State?

*An NFCA Commentary 8/06*

Family caregivers services are worth \$306 billion annually. This is a significant increase (drum roll please) over the previous estimate of \$257 billion, published in 2000. The estimates are the work of Dr. Peter Arno, PhD, a medical economist and professor in the Department of Epidemiology and Population Health at Albert Einstein College of Medicine. These statistics are used in multiple ways by the government, researchers, advocates and the media and therefore are important in the development of programs to support family caregivers and stories about the needs of family caregivers. NFCA worked with Dr. Arno to create a state-by-state breakdown of the data when the 2000 numbers were published and we are pleased to announce the publication of the 2004 state-by-state analysis of the prevalence and value of family caregiver services. An electronic version can be found at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

What makes these state statistics significant is that they are used to explain how large the caregiving population is and to justify the need for services. Although national policy is made in Washington, your access to services and benefits also has a lot to do with what happens at the state level.

A good example of this is the Family and Medical Leave Act. Passed in 1993, the Act provides employees at companies (minimum of 50 employees) the right to 12 weeks of unpaid leave every year to care for a new baby or a loved one with a serious illness. Many people have taken advantage of the law since its inception, but the biggest reason given for not taking leave is the loss of income

Californians didn’t think this was right, and now California is the first state to have passed a law that provides for paid leave. Employees can collect 55 percent of their weekly salaries, up to a maximum of \$728 a week for up to six weeks. The program costs an average worker about \$27 a year or \$2.25 a day. The obvious question, of course, is: If California has found a way to provide paid leave, why can’t other states? Family caregivers everywhere in America need this added benefit. And some may get it. Other states are looking at expanding the provisions of the Family and Medical Leave Act, some with paid leave and others by lowering the threshold size of companies that will need to comply with the bill.

California is ahead of the curve in other ways as well. It is the only state in the union that has a system of family caregiver resource centers — 11 in all. They provide consultations and care planning, support groups, legal and financial consultation, respite care, counseling, and education. To learn more, go to [www.californiacrc.org](http://www.californiacrc.org) or call the Family Caregiver Alliance at 800/445-8106 from California or 415/434-3388 outside the state.

The point is, family caregiving is hard, but how hard often depends on where you live. Some members of NFCA’s Caregiver Community Action Network (CCAN) have been active in trying to make things better for caregiving families in their state. A recent example is Robin Straight, LCSW from West Virginia. Robin is a geriatric care manager. She recently spent time educating her state’s legislators about the need for more respite programs for families dealing with Alzheimer’s disease. The legislators she spoke to admitted that they hadn’t known much about respite and why it was so needed.

In response to Robin's actions, and those of other advocates, the West Virginia Legislature recently passed the Alzheimer's Respite Bill. This legislation increases funding for respite care programs from \$250,000 to \$825,000, allowing every county in West Virginia to have respite programs for family caregivers of persons with Alzheimer's disease or a related dementia. The bill will provide funding for everything from in-home respite, to adult daycare for Alzheimer's patients and educational programs for male caregivers.

For the families throughout West Virginia whose loved ones have Alzheimer's or related diseases, this bill is welcome news. For the rest of America's family caregivers, this legislative victory is an example of grass-roots advocacy at work, and what it is possible to achieve.

On a day-to-day basis, most of us don't think about how what happens in Washington or in our state legislatures affects our lives as family caregivers, but it does. While not everyone is going to focus their energies on changing public policy, the way Robin did, we can all pick up the phone or send an e-mail when there is an issue we really care about; and we can let others know just how valuable family caregivers are — not just to the well-being of our loved ones, but to the rest of the people in our state as well. Family caregiving is hard. It always will be. But it doesn't have to be as hard as it is.

To find out what public programs for family caregivers are offered in your state go to: [www.caregiver.org](http://www.caregiver.org) and click on Caregiving Across the States.

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