THE BIMONTHLY NEWSPAPER OF THE AMERICAN SOCIETY ON AGING

AGING TODAY

Vol. XXVII, No. 4 PAGES 3 & 4 July–August 2006

ISSN: 1043-1284 www.agingtoday.org

HOW FAR HAS FAMILY CAREGIVING COME? A 30-YEAR PERSPECTIVE

Lynn Friss Feinberg, deputy director of the National Center on Caregiving at the Family Caregiver Alliance, San Francisco, received the American Society on Aging 2006 Leadership Award, at the association's spring conference in Anaheim, Calif. She based the following essay on her award lecture at the conference.

By LYNN FRISS FEINBERG

In the mid-1970s, before Alzheimer's disease became a household term, a San Francisco woman, Anne Bashkiroff, struggled with her own private hell in trying first to understand her husband's illness and then find help in caring for him as he slowly and insidiously lost his mind and ability to function. Bashkiroff's husband, who was in his 50s, eventually received a diagnosis of "presenile dementia" from a neurologist, and Anne was told the disease was progressive, untreatable and beyond the scope of the doctor's practice. She, along with Suzanne Harris and a small group of other family members who also were caring for relatives with debilitating brain-impairing conditions, formed the Family Survival Project Task Force (later to become the Family Caregiver Alliance) and held a town hall meeting in a church basement in San Francisco. It was 1976, 30 years ago.

Fast-forward to 2006. Today, real gains can be seen in the caregiving movement. Three decades of research clearly show that family caregiving is a public health issue—that family members who provide care to people with chronic or disabling conditions are themselves at risk, particularly when the care is for a person with dementia. Numerous studies have clearly documented that unrelieved caregiver depression, exhaustion, financial concerns and other care-related strain are major contributing factors to institutionalization, often resulting in higher public spending for long-term care.

SIGNIFICANT ACHIEVEMENTS

Important research evidence has helped forge significant achievements in public policy at the federal and state levels, especially two major federal laws. The Older Americans Act's National Family Caregiver Support Program, enacted in 2000, was the first federal law to explicitly acknowledge the service needs of families of older people in their caregiving role. All states now provide some caregiver services—yet, with the 2006 budget limited to $156 million, this national program is inadequately funded, leaving gaps in caregiver services that vary substantially from state to state, as well as within states.

The second major federal law to support caregiving families is the Family and Medical Leave Act (FMLA), enacted in 1993. This act was the first national legislation to offer important protections to working people to help them carry out both their work and their family responsibilities. The FMLA has been a great success, but there are gaps. Many employed caregivers—about 40% of the workforce—do not benefit at all, because they work for businesses with fewer than 50 employees. Moreover, most working people can't afford to take unpaid leave. A U.S. Department of Labor study showed that 78% of employees who have needed but not taken family or medical leave say they can't afford to do so.

The states, however, have led the way in designing and financing caregiver support strategies. Exam-

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ples are using state and federal funds to offer respite services; employing consumer-directed approaches permitting family members to be paid to provide care; improving the tax treatment of caregiver expenses; expanding family-leave benefits that are more generous than the federal FMLA (California was the first state to enact paid family leave); and using state revenues or alternative financing mechanisms, such as state lotteries, to raise funds designated for caregiver support programs.

Besides these initiatives in the last 15 years or so, other important gains in supporting family caregivers have also been made, particularly in technology. Technological advances are providing tools to help family caregivers that simply did not exist a decade ago. Examples include home medical monitors to detect possible wandering behavior and online medicine cabinets to monitor medication compliance.

Although caregiving is and will continue to be central to American family life, the United States must confront the reality that family care has changed. Family members are now asked to assume a health-management role at home with little or no preparation or training. Many must perform medical tasks that traditionally were carried out by healthcare providers, such as bandaging and caring for wounds, operating pumps and machines at the bedside or administering multiple medications. Susan Reinhard of Rutgers University, New Brunswick, N.J., has observed, "Family members are now being asked to take on tasks that would make nursing students tremble." Despite these additional demands, recent research has shown that among community-dwelling older people with disabilities, their sole reliance on family caregivers or friends has increased. Paid help is rare.

LESSONS OVER 20 YEARS

During the last 20 years in the field of aging, I've learned many lessons. In particular, I'd like to offer four observations that I feel would help professionals involved with caregiving to meet the challenges ahead.

Attitudes and views toward family caregivers influence public policies. There remains a pervasive ideology that government should not pay for care that families—especially women—provide for free. As more women assume leadership positions and elective office, we will, I hope, shift this thinking. Although caregiving is mainly a women's issue, it is also a concern for men. Today, more men are taking on caregiving roles. In our advocacy, we should not frame caregiving as just a women's issue—caregiving is a family issue.

American culture also needs to change attitudes about what constitutes a family. The concept of family must be broadened to reflect how we live today, inclusive of partners, friends and neighbors.

Another example of an attitude shift or expansion is related to the notion of *patient-centered* or *person-centered care*. I would suggest reframing the thinking behind these buzzwords to promote patient-centered *and* family-centered care. This change involves different, but not necessarily incompatible goals. The more inclusive term builds on the framework of the hospice and palliative care movement that recognizes the patient and the family as the unit of care.

BUILDING SUPPORT

Change is slow, but it is possible. In the last two decades, I have seen remarkable progress in caregiving and constancy of purpose in the advocacy for family caregiving. Family Caregiver Alliance (FCA, formerly the Family Survival Project) began as a small grassroots task force of family members with a strong motivation and determination to improve the quality of life for those caring for loved ones with cognitive impairments. Early on, the task force realized that the urgency of the personal challenges they faced would grow dramatically as the U.S. population ages. They also recognized that developing needed support services would require not only determination and perseverance, but also legislative action to change public policies.

When FCA's founders began meeting with local, state and federal elected officials in the late 1970s, no one wanted to grapple with what they were talking about. No one was willing to address the fact that serious illness not only affects individuals, but also the family. Public officials understood the problem, but the lack of a cohesive long-term care system in the United States provided scant support for their concerns.

Yet, FCA's family members persevered. They retained professional staff to assist them with carrying out their vision. Their task force became a nonprofit organization that now includes the National Center on Caregiving. They sponsored legislation to develop a model program in the San Francisco Bay Area for middle-income family caregivers. They believed deeply in their model program's broader applicability for families. FCA believed that wherever they live, family caregivers should have an assessment of their own needs and access to the same package of support services. They sponsored more legislation to

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replicate their innovative model program throughout California, resulting in the first-in-the-nation statewide system of Caregiver Resource Centers.

In addition, FCA's founding families and staff understood that the potential for exerting a positive impact on public policy meant collecting uniform, statewide data across program sites. They grasped that in replicating their program it was important to instill in the new centers the *spirit* of the program—its philosophy and basic principles—to recognize, support and strengthen family caregivers, not just the how-tos and structural aspects of the program. They began partnering with other groups, programs and researchers who were tackling this issue. And FCA helped create a national movement on caregiving—all within the relatively short time span of 30 years.

A HUMAN RIGHTS ISSUE

The personal drives action. When it happens to you, when it becomes a personal issue in your own family, when you are a decision-maker, you are more likely to act. There are numerous examples of federal and state lawmakers who introduced caregiving legislation or embarked on new initiatives because of their own personal experiences. One case in point is U.S. Interior Secretary Dirk Kempthorne, former Republican governor of Idaho, who himself faced caregiving. When he chaired the National Governors Association, he launched a long-term care and caregiving agenda that included support for families caring for elderly family members.

Chronic illness and caregiving are no longer abstract issues for many professionals in aging. We are not just studying and teaching aging, or planning and delivering services for older people, we are also aging and, more often than not, experiencing caregiving firsthand. It is up close and personal, and often the U.S. nonsystem of long-term care fails us, too.

Advocacy can be bold and creative. Perhaps the time has come to consider reframing family caregiving as a human rights issue, so that family members are viewed as individuals with rights to their own support services and assessment of their own needs. This view is now the law of the land in the United Kingdom. Why not in the United States? Today, healthcare and long-term care are essentially segregated by the sole focus on the individual beneficiary. Family members are often invisible in the care process, yet families provide the bulk of everyday care and face their own health risks as a result. With the aging of the boomers, the need for forward-looking policies and programs to recognize, value and sustain family care has never been greater.

Where is the sense of advocacy that motivated such leaders as the late Gray Panther founder Maggie Kuhn, FCA founders Anne Bashkiroff and Suzanne Harris, and others who created grassroots movements with lasting results? Maybe it is time to organize family caregivers as a political force for thoughtful and lasting change.

Family care issues offer the potential to transform long-term care. We have come a long way from the grassroots survival of families in the mid-1970s. Yet, we still have a long road ahead. Let's be bold and creative—let's move beyond our talk to positive action. ❖

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