Family Caregiving
Sharing Strategies, Celebrating Progress
The National Health Council is a private, nonprofit umbrella organization of 117 national health-related organizations. The Council is a forum for diverse groups to build consensus on patient needs, and it provides information on and advocates for quality health care for all people. Its core membership includes more than 50 organizations representing people with chronic diseases and/or disabilities, such as the Alzheimer’s Association, the American Cancer Society, the American Diabetes Association, Easter Seals, the National Multiple Sclerosis Society, the Arthritis Foundation, and the American Heart Association. Other Council members include professional and membership associations, such as the National Family Caregivers Association, National Hospice and Palliative Care Organization, and the American Medical Association; nonprofit organizations with an interest in health, such as AARP; and major pharmaceutical and biotechnology companies.

Sponsored by the Rosalynn Carter Institute for Human Development, the National Quality Caregiving Coalition includes national associations, groups, and individuals with interests in and active agendas that promote caregiving across all ages and disabilities throughout the lifespan. The Coalition’s more than 35 member organizations include the Family Caregiver Alliance, the National Family Caregivers Association, Children of Aging Parents, The National Alliance for Caregiving, the Well Spouse Foundation and other national caregiver groups; the American Hospital Association, the American Association on Mental Retardation, the American Psychological Association, and the U.S. Centers for Disease Control and Prevention.

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Conference Report
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Table of Contents

Introduction ............................................................................................................... 4
Creating New Synergies ............................................................................................ 4
The Faces of Caregiving ............................................................................................. 5

Signs of Progress: Increased Caregiver Support from the Health Care System .......... 6
Government Policies and Programs ......................................................................... 6
Health Care Organization Policies and Programs .................................................... 17

Signs of Progress: Increased Support for the Services Caregivers Need ............... 23
Research: Caregiver Needs and Preferences ............................................................ 23
Reaching Out to Caregivers: Innovative Approaches .............................................. 29

Signs of Progress: Increased Support for Balancing Work and Family Commitments .................. 38
Government Programs ............................................................................................ 38
Employer Programs .................................................................................................. 40

Conclusion: Caregiving is Personal ........................................................................ 45
Introduction
Creating New Synergies

The National Health Council has been specifically addressing family caregiving issues since 1998, when it held a consensus development conference to create an action plan for improving caregiver services and support nationwide. That *Agenda for Action* identified objectives and action steps for three key priorities: increasing caregiver support from the health care system; increasing support for services caregivers need; and increasing support for balancing work and family commitments. The Council widely distributed the *Agenda* and created a long-term plan for collaborating with interested organizations to monitor and share progress.

The first step in that plan was conducting a survey in 2001 to determine what governments and organizations had done to move forward on *Agenda for Action* priorities. The survey found encouraging signs of progress and identified program models that could be adapted and replicated to expand their impact. The Council captured these developments in a written *Progress Report*, which many groups have already used to find program ideas, identify potential partners, and learn from others’ experience.

This conference was the next step in the process. Joined by the National Quality Caregiving Coalition of the Rosalynn Carter Institute, the Council designed this meeting to celebrate the important progress that has been made for family caregivers, to provide a forum for organizations to share their successful program approaches, and to move caregiver support to the next level by creating new synergies and offering participants concrete steps their organizations can take now.

The Council defines family caregivers as immediate family, relatives, partners or close friends who directly provide or manage care, emotional support, or advocacy for people of any age with chronic illnesses or disabilities. A diverse group with varied individual needs and cultural and ethnic differences, family caregivers also have many common bonds in the joys and rigors of caregiving. While their efforts help keep the formal health care system solvent, their own needs have often been overlooked and unmet. On their behalf, and for all of us who will one day need care, we must work hard to sustain and advance the progress this conference documents.

Myrl Weinberg, CAE
President
National Health Council
The Faces of Caregiving

Family caregiving is a profoundly personal issue for most people, and stories about caregivers speak of energy, intellect, and heart. The Rosalynn Carter Institute has seen the many faces of caregiving since 1987 when it was created at Georgia Southwestern State University to honor Mrs. Carter. At first the Institute focused on caregivers of the mentally ill, but because caregiver needs were clearly so great, RCI’s perspective grew to encompass the full range of family caregiving situations. The National Quality Caregiving Coalition grew out of these efforts, and today more than 30 organizations work together to support high-quality care.

Most family caregivers do not call themselves by that name. Instead, they see themselves as trying to be good sons, good daughters, good wives, or good husbands. The profile of the “average” caregiver is a married woman aged 55 to 64 who provides about 19 hours of care per week for five years, either in her home or outside (45%). Half of family caregivers are employed, and one-quarter have annual incomes of $20,000 or less. Yet no caregiver is average, and people of all ages and both genders provide care for relatives and friends in many situations.

In fact, caregiving is a part of life that occurs not just at the end of life but throughout the lifespan. Children learn from their families at an early age about the empathy, concern, and values of caregiving, and they go on to see other models of care from teachers at school. They get married and commit to caring for their spouse if health problems arise. When babies are born, they provide another kind of care, and they may seek help with child care when they return to work. In middle age and in the middle of their careers, they are likely to be caring for teenagers — and for older parents, as disabilities begin to occur.

When people retire or when their children are grown, they commonly expect to be free from responsibilities. But life may take a different twist, and caregiving may begin all over again as older parents need more significant amounts of care, grandchildren need care their children cannot provide, or friends/colleagues need care but may not have a family to provide it. In this reality, 70-year-olds may be caring for 90-year-olds.

According to a recent study by the Rosalynn Carter Institute, caregivers live a “marathon existence” that puts them at higher risk for depression and requires community resources to support and supplement their own ceaseless efforts. This need can only grow as medical care extends the lifespan and helps more people live with chronic diseases and disabilities that would once have been fatal. Society must provide the support caregivers need throughout the life cycle. This conference is a benchmark in our dialogue about these critical issues.

Ronda C. Talley, PhD, MPH
Executive Director
National Quality Caregiving Coalition
of the Rosalynn Carter Institute
Signs of Progress: Increased Caregiver Support from the Health Care System

Government Policies and Programs

Federal Programs That Affect Family Caregivers

Edwin L. Walker, Director, Center for Wellness and Community-Based Services, U.S. Administration on Aging

Two federal programs now provide increased support to family caregivers: the National Family Caregiver Support Program (NFCSP) and the New Freedom Initiative, the federal response to the Olmstead Supreme Court decision on the rights of people with disabilities to community-based care.

National Family Caregiver Support Program

Finding – and funding — temporary care for a mother with Alzheimer’s while her caregiver daughter recovered from an automobile accident… Supporting respite care and diapers for an 80-year-old grandmother caring for her 23-year-old granddaughter (who has AIDS) and her children… Providing emergency nursing home care, and helping sort out alternative care, for an older woman whose caregiver was killed in the attack on the Pentagon on September 11… .

The NFCSP provides federal funds to states and territories to support people like these: the caregivers of older Americans and children. Administered by the Administration on Aging (AoA), the program includes five core services:

- Information about health conditions, resources, and community-based services.
- Assistance to caregivers in finding the help they need.
- Counseling, support groups, and caregiver training.
- Respite care.
- Other services (a catch-all category that is designed to cover various caregiver needs, such as home modification, incontinence supplies, air conditioning for a caregiver’s home, nutritional supplies, assistive devices).

In 2002, the NFCSP had a budget of $128 million, which the states have used creatively to develop such programs as using telehealth technology to link caregivers to medical expertise; connecting caregivers to on-line support groups with donated computers; and training retired volunteers to provide respite care.
Overall, state use of the funds falls into three categories:

- **Forming new partnerships to expand services.** New collaborations have included working with: Faith in Action volunteers (see page 31) to reach underserved areas; the ARCH National Respite Network to assist caregivers of mentally retarded people; Generations United to provide services for grandparents caring for grandchildren (see page 33); and Easter Seals to enhance transportation options for people with Alzheimer’s Disease (see page 42).

- **Improving access to services.** One example is a project in Seattle, Washington, that developed a caregiver training program to build skills and increase caregivers’ confidence in their caregiving abilities. Other states have adapted this program to meet their needs.

- **Reaching out to special populations.** For example, in Virginia male caregivers receive special services and outreach, targeted particularly to the state’s significant population of retired military personnel.

**AoA Activities**

Besides providing funds to the states and monitoring their use, AoA has solicited input from caregivers about their needs and how the NFCSP should help. Town hall meetings, focus groups, advisory boards, and a series of nine listening sessions around the country have helped bring caregivers into the program process. Along the way, many caregivers have learned about federal support for which they are eligible, through Medicaid or the Veterans Administration, for example. AoA has also helped caregivers learn how to apply for these benefits.

To improve coordination of services, AoA has formed an intradepartmental task force to identify caregiver support activities that occur throughout the federal government. For example, AoA is working with the Centers for Medicare and Medicaid Services (CMS), whose eligible beneficiaries can receive support for respite care services. It is also collaborating with the Centers for Disease Control and Prevention (CDC) to break down the barriers between the aging and public health networks, making services more consumer-oriented and easier to access.

Another key priority is teaching Americans that family caregiving is a public health issue. Not only do caregivers themselves need to learn about the help available to them, but health and social service professionals also need to be aware of the toll caregiving takes on the health of the caregiver — and to ask about caregiver needs when dealing with a care recipient. To improve awareness, AoA has developed a public service announcement for public television; is working to create a national public awareness campaign; and is helping to build a national grassroots caregiving coalition.
New Freedom Initiative

The New Freedom Initiative encompasses all of the federal government’s disability policies, including action on employment, transportation, housing, and long-term care. With the recent Olmstead decision, it is now unconstitutional to isolate a disabled person in an institution if the person is able to live in the community. Since most programs have been institution-based in the past, many changes are needed to reorient services to a community-based model. The AoA’s role is to get public input on needs and barriers for disabled people in receiving community-based care; to assist the states in implementing programs that increase access to community-based care; to assess their efforts; and to coordinate federal efforts to comply with the Olmstead decision.

At the federal level, nine agencies, such as AoA, CMS, CDC, and the National Institute for Mental Health, have sent a report to the President with a blueprint for change. The report includes 400 solutions to improve community living for the disabled, with specific ideas for caregiver support. The Administration is also seeking additional funds from Congress to conduct a ten-year demonstration project on Medicaid-funded respite care in the states and to improve the integration of community services for the disabled population.

The Lifespan Respite Care Act of 2002
Senator Hillary Rodham Clinton

In May 2002, Senator Clinton, along with Senators Snowe, Mikulski, and Breaux, introduced Senate bill 2489 to assist family caregivers in accessing affordable and high-quality respite care. The bill, if enacted by the Senate and the House of Representatives, would fund competitive grants to states and private organizations to:

- Improve and coordinate dissemination of respite care information and resources.
- Provide, supplement, or improve respite care services.
- Promote innovative, flexible, and comprehensive approaches for delivering respite care, training of respite care workers and volunteers, and training to assist caregivers in making informed decisions about respite care.
- Evaluate respite care service and training approaches and disseminate information about successful strategies.

The bill defines “lifespan respite care” as “a coordinated system of accessible, community-based respite care services for family caregivers of individuals regardless of the individual’s age, race, ethnicity, or special need.” As introduced, it calls for a $90.5 million appropriation for Fiscal Year (FY) 2003, with budgets increasing over five years to $200 million in FY 2007.
Each year, about 26 million Americans care for one or more adult family members or friends who are chronically ill, disabled, or at the end of life. Families also care for about 18 million children who have chronic conditions that demand special caregiver supervision and about 4 million people of all ages who have mental and developmental disabilities. If the nation paid for the care families and friends provide, it would cost about $200 billion each year.

But the numbers are superficial. The real story is about caregiver sacrifice and commitment. At the press conference held to introduce the Lifespan Respite Care Act, a mother told her story, which illustrates the challenges caregivers face and the need for a national policy of providing respite care. The mother, Heather, cares for her four-year-old daughter whose rare illness makes her totally dependent on her family, including the need for constant monitoring to prevent self-destructive behavior. Heather has pieced together with great effort 164 hours a year of respite care through the state of Maryland. She uses the funding to hire someone to care for her daughter and, in fact, brought a respite worker with her to the press conference to watch the child while she spoke. Exhausted now, Heather faces many more years in this intense caregiving role.

This example shows that while family caregiving is unpaid, it is not costless. It creates emotional, physical, and financial strains for caregivers, and we need to take national responsibility for giving them the support they require to continue their efforts. Some states and organizations do provide respite services. For example, United Cerebral Palsy in Nassau County, New York, gives respite care to 70 families – but it has 200 more on its waiting list.

The Lifespan Respite Care bill provides substantial funds to develop a coordinated system of respite care that covers all those who need it and includes funds to train respite workers to ensure high-quality care. Trained workers should also get a decent wage, although minimum wage is the current norm.

Some in the Senate have questioned the funding levels the bill requests. Others say the language is “too broad” and will be used for “babysitting.” With the help of the National Respite Coalition, the bill was crafted to be broad, inclusive, and flexible. Caregivers need financial support and services, and they don’t need to be micromanaged. As a result of the legislation, at least we are having this important conversation in the Congress.

All of us can play a role in getting the Lifespan Respite Care bill passed. Tell your stories to your senators and representatives. Voice your support for the bill and stay in touch as the legislation moves through the Congress. While women provide most of the family caregiving in this country, caregiving is not just a women’s issue. It is a family issue and a quality of life issue. As a society we need to value caregiving and caregivers; it is a reflection of who we are. In some countries, the disabled are shunned and caregiving is not valued highly. Americans do value caring for our families, and now it is time to support those who provide this care.
Advocating for Lifespan Respite: The Role of the Lifespan Respite Task Force

Jill Kagan, Chair, National Respite Coalition of the ARCH National Respite Network, Founder and Facilitator of the Lifespan Respite Task Force

The Lifespan Respite Task Force is a highly diverse group of partner organizations with a common goal: an America where respite care is readily available and easily accessible to all caregivers. It is a working group of the National Respite Coalition, national organizations representing individuals with disabilities, chronic illness, and mental health conditions; children and families including foster care families and grandparents caring for grandchildren; the aging; family caregivers; the faith-based community; health and long-term care; education; and abuse and neglect prevention. The task force defines respite care, which includes crisis care, as “temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs, or who may be at risk of abuse or neglect.”

State policies supporting coordinated lifespan respite care in states such as Oregon, Nebraska, and Oklahoma generated momentum for national lifespan respite policy. The task force came together for the first time in May 2000 at the Lifespan Respite Summit sponsored by the National Respite Coalition. At this meeting, they shared information, developed a vision, and drafted a discussion bill providing for national lifespan respite policy.

Many groups and individuals provided feedback on this bill, including staff from Senator Clinton’s office who knew that Mrs. Clinton would want to be involved. She and her staff further refined the bill with additional input from the task force, found cosponsors in the Senate, and submitted the legislation in May 2002. The strength and diversity of the task force made it easy to reach out to the House of Representatives for support, where a bill similar to Mrs. Clinton’s will also be introduced.

Task force member organizations have made passage of the Lifespan Respite Care bill a top legislative advocacy priority for 2002. Members have also been helpful in providing credible data on family caregiving issues and needs, and the ARCH National Respite Network is piloting a national assessment of outcome measures to be used in evaluating the impact of respite care on family caregivers.

How was this diverse group able to work together effectively? Two principles were key. First, the task force had incremental goals, accomplished step-by-step, that created and maintained motivation. Second, everyone had ownership of the effort, which promoted and reinforced their commitment.

It is important that all interested individuals and organizations lobby Congress to pass this bill, beginning with the members of the appropriate committees. (In the Senate, the Health,
Education, Pension and Labor Committee has already passed the legislation, which will move on to consideration in the full Senate. In the House, the Energy and Commerce Committee will be responsible for the bill’s first review.)

State Responses to the Olmstead Decision: Impact on Family Caregivers
Wendy Fox-Grage, Program Principal, National Conference of State Legislatures

To comply with the 1999 Olmstead decision, states are required to 1) have a plan for shifting from an institutional model of care for people with disabilities to a home and community delivery system and 2) move people quickly off waiting lists for community-based services. According to a recent study conducted by the National Conference of State Legislatures (NCSL), 42 states and the District of Columbia now have task forces working on plans for responding to the Olmstead decision. These task forces are inclusive of all those with mental and physical disabilities.

Although it has been three years since the Olmstead decision, the short-term impact on family caregivers has been little to none, because states continue to be in a planning stage rather than implementing new programs. One reason for the delay is a shortfall in state budgets. While Medicaid expenses are rising an average of 25%, state revenues are only growing by 5%. As a result, states are cutting their Medicaid budgets at a time when new dollars are needed to implement Olmstead plans. In addition, most state task force plans are not yet comprehensive, lacking timelines, budgets or both. Mississippi, Missouri, Ohio, and Texas currently have the best elaborated plans, with a clear vision for a new approach to caring for people with disabilities and specific strategies for addressing such needs as housing, transportation, assessment, family-centered planning, staffing, data collection, education, and outreach.

Some positive trends are occurring, however, as states begin to view disability as more than a health care issue.

A few examples of state action include developing study commissions to assist in planning; creating mechanisms for direct payments to consumers (e.g., in Colorado, Florida, and Maine); initiating a single-point-of-entry

Positive Trends in State Programs

- Some states are beginning to improve their individual assessment systems, which is a relatively undertaking.
- Federal systems change grants are jump-starting state programs to transition disabled people from nursing homes to community-based care.
- Staffing for related programs is increasing from very low levels to low levels.
- Data and information systems are beginning to be improved.
system for disabled services (Florida); and educating nursing home residents and their families about options for moving toward community care (Maryland).

All those with an interest in improved community services for people with disabilities should consider joining the Olmstead task force in their state. For contact information or more details about the NCSL report, go to www.nclsl.org, and click on policy issues, health, and long-term care.

Overview of State Caregiving Policy Trends
Lynn Friss Feinberg, Deputy Director, National Center on Caregiving, Family Caregiver Alliance

Family caregiving is a growing issue for states both because of the need to control nursing home costs and because of the rising societal value placed on caregiving as more women and caregivers now hold elected offices. The focus on caregiving can only increase as the Baby Boom generation gets older. In fact, the first Boomers begin to turn 65 in 2011, just nine years away. This large population will demand high-quality, affordable, home-based care and government support for caregiving families.

The Family Caregiver Alliance (FCA) has conducted two surveys of state caregiving policies, one in 1999 before passage of the National Family Caregiver Support Program and one in 2002. Both studies identified innovative approaches to helping caregivers and a growing trend toward services that are broad-based, flexible, and consumer-directed.

1999 Survey: 15 State Caregiver Support Programs

FCA surveyed caregiving policy trends in California, Florida, Illinois, Iowa, Michigan, New Jersey, New York, North Dakota, Ohio, Oregon, Pennsylvania, Texas, Virginia, Washington, and Wisconsin. The survey found that a variety of state agencies administer support programs for caregivers of different ages caring for loved ones with different diseases and disabilities. Although some states were moving towards a more family-oriented assessment process, most still provided a formal assessment only for care recipients. The service most often funded was respite care, although how respite was defined, delivered, and funded varied widely, as did eligibility criteria for receiving it. Half of the programs allowed a family member to be paid to provide respite care.

After reviewing state approaches, researchers identified eight best practices in state caregiver support. These included:

- Recognizing the term “caregiver” in state legislation that mandates state funding.
- Offering an array and choice of support services and respite options.
- Considering the client to be the family or informal caregiver (or both the caregiver and care recipient).
• Promoting consumer direction and a family systems orientation.
• Using broad eligibility criteria that included those with middle incomes.
• Collecting statewide data on family caregivers.
• Expanding the program’s budget, services, and/or client base.

Five states were cited for best practice programs: California’s comprehensive Caregiver Resource Centers, New Jersey’s Statewide Respite Program, New York’s Consumer and Family Support Services, Oregon’s Lifespan Respite Program, and Pennsylvania’s Caregiver Support Program.

2002 Study: Case Studies of Ten States

This study looked at Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas, and Washington to determine how these states are using NFCSP and other federal and state funding sources to support caregivers. While full results are not yet available, researchers have identified many interesting examples of the kinds of support caregivers are now receiving.

In Alabama, for instance, NFCSP funded in-home haircuts for caregivers. The local Area Agency on Aging (AAA) also helped a caregiver install indoor plumbing by finding a plumber and arranging for lower-cost supplies from a local hardware store. In Hawaii, NFCSP funds paid for installation of Lifeline equipment (emergency call system for people who fall), while in Pennsylvania it bought babysitting services for a caregiver with young children and a washer/dryer for a caregiver with arthritis who had been washing clothes by hand and hanging them outside to dry.

2002 State Health Priorities: Impact on Caregiver Support

According to the National Conference of State Legislatures, 20 states are addressing the financing for family caregiver programs. These states are using such approaches as providing services through state programs; giving caregivers the funds to buy their own community-based services; offering tax incentives (credits, deductions, or both) to help with caregiving expenses; using technology to provide information; and sponsoring public information campaigns, such as the “Alabama Cares” campaign, designed to make people aware that they are caregivers and of the services available to them. In addition, Maine and Vermont have passed state laws that allow families to take more time off than the federal Family Medical Leave Act (FMLA).

Despite these positive trends, the top three health priorities for the states in 2002 are not specific to caregiving or long-term care. Instead, they focus on dealing with the Medicaid budget shortfall, maximizing federal Medicaid payments, and addressing health work force shortages. In this environment, it will be important to continue to advocate for family caregiving so that caregiver needs are very visible during critical budget decisions. Unfortunately, it appears that state budget shortfalls may increase further in 2003, so the
NFCSP may not create concrete change in the short term. It will also be important to ensure that states and society do not overburden families by expecting them to help control health care costs at a time when family caregivers’ valuable contributions to health care solvency are becoming more recognized.

**California’s Caregiver Resource Centers**

Kathy Kelly, Executive Director, Family Caregiver Alliance

California’s Caregiver Resource Centers (CRCs), a single-point-of-entry system offering comprehensive caregiver services, began as a pilot project conducted with the Family Caregiver Alliance (FCA) in 1983. The California legislature subsequently mandated statewide replication of the program, with the FCA as a statewide consultant. In 2001, the system included 11 CRCs across the state with a budget of $11.75 million.

In the CRC model, family caregivers of those with adult-onset cognitive impairment are the clients, and they can turn to CRC for services throughout the caregiving experience. Unlike a traditional caseload model, the CRC role ends when a family is stabilized in a caregiving situation and only begins again if needs change and caregivers request additional help. Phone reassessments at six-month intervals help keep caregivers in the system. In addition, family caregivers are the care managers for their impaired relatives.

The CRCs offer a wide choice of services and options, including:

- Caregiver in-home assessment.
- Family consultation and care planning to determine needs and make choices.
- Family support services, including individual counseling, family meetings, group counseling, classes for caregivers, and both face-to-face and on-line support groups.
- Legal and financial consultation, in which the CRC contracts with eldercare attorneys to provide one-and-a-half hours of free consultation.
- Respite care in many forms, including in-home respite where the CRC pays a relative or an agency to provide care; adult day services; week-end respite camps; overnight care; emergency care; and caregiver retreats. Caregivers can mix and match these services.
- Caregiver training and education programs, which 30,000 Californians attend annually.
- Information for caregivers through a wide variety of printed fact sheets, web resources, and telephone assistance.

The CRC system emphasizes local flexibility for each center, but all operate under statewide quality standards. For example, all centers have a single point of entry for caregiver services, use a uniform assessment tool, and offer consistent staff training. When caregivers contact CRC sites for information and assistance, the centers complete a uniform intake form.
As the statewide consultant, the Family Caregiver Alliance reports to the California Department of Mental Health. In addition to providing centralized information and feedback to all CRCs, FCA coordinates all efforts to minimize fragmentation of services. The Alliance is also responsible for policy and program development, as well as research, education, and staff training.

The typical CRC client is a 60-year-old woman who has cared for her husband with Alzheimer’s disease for about four-and-a-half years, providing an average of more than 12 hours of care a day. Nearly half of families served have a median annual household income under $30,000 (in 1999 dollars). They say that caregiving affects their well-being, with 57% reporting being depressed, 43% perceiving the burden to be quite or extremely high, and 40% saying their health is worse now than it was five years ago. Their greatest needs are for information (69%), emotional support (68%), and respite care (65%), though significant numbers also need other types of support such as help with behavior management, legal and financial issues, and assistance with placement.

A major current focus of CRC development is expanding the use of technology to improve caregiver services and CRC responsiveness. For example, FCA is directing a project to put client records on-line so that family counselors in the field will have immediate access to them and be able to tailor services to meet current family needs.

New Jersey Ease for Caregivers
Barbara Fuller, Program Manager, New Jersey Department of Health & Senior Services

New Jersey has offered an array of services for caregivers since the 1980s. Unlike the integrated model of California’s Caregiver Resource Centers, however, disparate agencies and offices have operated New Jersey’s caregiver programs with little coordination. A recent reorganization and funding from the National Family Caregiver Support Program is now enabling New Jersey to create a unified system of caregiver support: New Jersey Ease for Caregivers.

Programs for Caregivers

Support for New Jersey caregivers includes:

- State-funded respite care for families caring for adults age 18 and older. Families receive up to $4500 per year in services, with options of hourly, overnight, and one- or two-week respite care, plus respite camps. Residents pay for services on a sliding fee scale.
- Adult day services for caregivers of people with Alzheimer’s disease and related disorders. A legislated program with state funding, this program offers care for up to three days a week in a medical or social setting.
• Group education. State funds enable caregivers of older people to attend *Caring for You/Caring for Me*, a program developed by the Rosalynn Carter Institute. State dollars also trained professionals to lead the group classes, which nonprofit groups offered three times per county statewide in 2001.

• In-home caregiver education and support. The state’s 21 respite care programs administer these services, which include an in-home assessment by a registered nurse of the caregiver’s learning needs and up to five in-home training sessions to meet them. In addition, caregivers can receive in-home short-term counseling by a clinical social worker or advanced practice psychiatric nurse.

• Respite care, caregiver education, and reimbursement for family caregivers. These services are administered by Area Agencies on Aging and paid for through expanded Medicaid waivers and new state funding. This approach enabled New Jersey to expand services for caregivers of older people.

**Moving Toward Integration**

In 1996, New Jersey merged health and aging programs into one agency, the Department of Health & Senior Services. The state also worked with counties to design a single point of entry for senior services using a toll-free number. Under this program, *New Jersey Ease*, parallel and/or competing services were merged into 21 coordinated county systems. These systems are operated by nonprofit partner organizations or county government agencies and administered by each county’s AAA. While each county system meets its own unique needs, all follow the same overall guidelines, use a uniform assessment tool, provide extensive staff training, and comply with state standards of service performance.

This model is now being expanded to provide coordinated, single-entry services for caregivers. With funds from the National Family Caregiver Support Program, the state is conducting a three-year demonstration program, *New Jersey Ease for Caregivers*. During year one, a culturally diverse advisory committee is developing caregiving screening, assessment, and care planning instruments; a caregiver staff training curriculum; caregiver service coordination policies and protocols; and a caregiver website. All of these programs will view caregivers as “legitimate consumers” in the aging services system. These approaches will be tested and refined in three pilot counties during year two and implemented statewide in year three. At this time, New Jersey will also publish an evaluation of the project and disseminate county “best practices in caregiver services” through reports and a conference.
The United Hospital Fund’s *Families and Health Care Project*

Debbie Halper, Vice President and Director, Educational and Program Initiatives

While most family caregiving takes place at home, care recipients are often hospitalized during the course of chronic illness or disability. When researchers from the United Hospital Fund’s (UHF) *Families and Health Care Project* asked focus groups of family caregivers what they needed from hospitals, the number one issue raised was improving transitions – to the hospital from home and from the hospital to home or another facility. Key concerns included the following.

- A chaotic admissions process.
- An increased sense of caregiver sadness, as hospitalization led families to confront the patient’s deterioration.
- Difficulty getting information from hospital staff about the patient’s condition and results of tests or procedures.
- Feeling invisible or unwelcome in the hospital setting.
- Inadequate training for health care tasks they would have to assume at home; dismissive attitudes about their fears.

Findings of a random sample telephone survey echoed focus group results and also revealed that providing care was more difficult after a family member had been hospitalized. Caregivers had to take responsibility for assisting with more personal care tasks and more household management tasks.

In response, the UHF has provided grants to hospitals to develop approaches to making family caregivers part of the health care team and to ease hospital transitions. One example is a program at Cabrini Medical Center in Manhattan that has created two acute care dementia units called Windows to the Heart. These units provide a high level of empathic care to family caregivers while patients are hospitalized. Cabrini provided staff training in how to work with families and focused on creating a family-centered culture at the facility.

Another grantee, the Brooklyn Hospital, partnered with the Wartburg Lutheran Home for the Aging to reduce caregiver strain and improve follow-up care. In this project, a gerontologic nurse practitioner works with families while the patient is in the hospital, teaching family caregiving techniques and following up with them after discharge via home visits and phone
calls. Maimonides Medical Center took a similar approach and also offered a caregiver hotline that families could use to ask questions or get help after the patient went home.

Other innovative ideas included developing an interactive website for family caregivers with comprehensive references and information (Jamaica Hospital Medical Center); creating a caregiver and professional partnership, in which both partners took part in educational programs (Mount Sinai Hospital); creating tools to help families and staff communicate better (New York University Medical Center); and developing a social work liaison program that allows families to work with the same social worker during and after hospitalization (Peninsula Hospital Center).

Success Factors

Approaches like these produced tangible benefits for caregivers, who reported reduced burden and greater confidence in patient care. While creating institutional change to support caregivers is not without challenges (especially difficulties relating to hospitals’ financial problems, staff turnover, and engaging senior leadership), the *Families and Health Care Project* identified a number of factors associated with positive outcomes (see box).

The new focus on caregiving has had benefits for hospitals as well as for caregivers, including improving staff-family interactions and expanding community linkages. When the grants are over, grantees expect the innovations to be sustained, as family caregiving has become a real part of the professional and policy agenda. The United Hospital Fund will be disseminating detailed information about all the *Families and Health Care* projects in a special report, national conference, workshops, and articles in major publications.

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Success Factors in Hospital Programs

- Gathering and analyzing data on people served and benefits gained.
- Making the effort visible throughout the institution and celebrating accomplishments.
- Communicating widely about the program and expectations for staff.
- Ensuring support from all levels of administration.
- Conducting staff training formally and informally; for example, approaches included training in departments or committees, during rounds, as part of medical student rotations (including home visits to caregivers), and a retreat to help staff rethink the care process.
- Being flexible and focusing on the goal, caregiver support and involvement, rather than on process or “the rules.”
- Trying several approaches to see what works best in a particular environment.
Caregivers as Colleagues at the Hospice of Michigan
Jeanne Parzuchowski, RN, MS, ONC, PhD

The Hospice of Michigan (HOM) has sponsored four initiatives to empower caregivers and enhance the hospice’s ability to assist family members. These include using a validated tool to measure caregiver burden, providing a program for caregivers of congestive heart failure (CHF) patients, linking caregivers to professional assistance through telehospice, and developing a manual for caregivers of Alzheimer’s patients.

Measuring Caregiver Burden

The Caregiver Burden Index is a short, simple questionnaire that offers a snapshot of how well caregivers are coping with the demands of their responsibilities. By using this standard tool, HOM can identify problems in caregiver coping as they occur and connect the family to sources of support. For example, if a caregiver needs community services or emotional support, a social worker helps link him/her to appropriate resources. Volunteers might provide other help to meet identified needs. Just having the questionnaire opens conversation about issues the caregiver might be reluctant to bring up spontaneously.

Supporting CHF Caregivers

Managing congestive heart failure can be particularly stressful for patients and caregivers. In rural Michigan, geographic isolation can heighten family concerns. HOM is part of a regional coalition that includes a community hospital, a cardiac rehabilitation facility, a home care agency, and individual physicians that work together to integrate care from time of diagnosis to death.

In this model, the patient and caregiver receive equal attention, and every care provider follows a standard protocol and uses standard teaching materials and measurements. The caregiver burden questionnaire described above is one assessment tool, and another questionnaire measures patient burden. This approach facilitates coordination of care and transitions and empowers caregivers by providing a consistent approach.

Telehospice

Funded by a grant from the National Telecommunications and Information Administration, the Michigan State University/University of Kansas Medical Center Telehospice Project uses a TV desktop videophone to link hospice services to families caring for patients at home. Caregivers and patients can ask questions of health professionals and receive support “face to face” without the need for travel. HOM is working with its clients and caregivers to assess satisfaction with this approach and with their communication experiences. So far, families have had favorable responses to being able to see the professional who is offering support.
Alzheimer’s Family Caregiver Manual

Designed for caregivers of those with advanced dementia, this manual focuses on 11 common medical choices associated with this patient population. Written in lay language, it helps empower caregivers by providing needed information, and it enables them to play a constructive role on the health care team.

Managed Care Services for Caregivers: Sierra Health Services Senior Dimensions
Diane Smith, Vice President, Sierra Health Services

Sierra Health Services, a Nevada-based managed care organization, administers the Senior Dimensions social health maintenance organization (SHMO), which is a Medicare + Choice plan offered under contract with the Centers for Medicare and Medicaid Services. This plan, one of four in the United States, is designed to provide more services than a standard Medicare HMO. The model includes many services that address caregiver needs and concerns.

A key element of the model is care coordination, which is an interdisciplinary approach to care using the primary care system. In this approach, patients in the SHMO plan are assessed and monitored by plan nurses and social workers, who screen for risks and develop a care plan that includes all the community health providers the patient needs. The plan is reassessed based on patient progress and needs. Professional care coordination as a benefit relieves caregivers of a responsibility usually left to them.

SHMO’s chronic home care program alleviates another caregiver concern: supervising the medical and emotional well-being of the care recipient at home. In this program, home health professionals are trained to identify and manage the psychological, functional, and social needs of plan members. Services include situational counseling, nutrition, transportation, maintenance therapy, home safety, personal care, and homemaker assistance, as well as a personal emergency response system.

Services that directly benefit caregivers include a varied menu of respite care options, including in-home companionship, adult day care, short-term group home care, and short-term institutional care. The plan trains staff for these services to work with patients and families as clients. Senior Dimensions also provides well-attended training for family caregivers and support groups for families caring for people with Alzheimer’s disease or congestive heart failure.

Membership in the Social HMO has increased among all eligible age groups, and consumer satisfaction has been very high with services provided. In addition, the program has been shown to reduce hospitalizations for care recipients and overall costs.
Better Coordination of Care: A Model for Managed Care Organizations
Katie Maslow, MSW, Director, Acute and Managed Care, Alzheimer’s Association

Since 1997, the Alzheimer’s Association and the National Chronic Care Consortium have been working together to design, implement, and evaluate a model of care that coordinates medical and supportive community services for people with dementia. To carry out the project, local Alzheimer’s Association chapters are working in partnership with a health care organization and (in a few sites) with other community agencies in seven sites across the country. An important objective for the project is to involve and support family caregivers, and each part of the coordinated care model addresses this aim.

The model, which took about two years to create and find funding to implement, has four parts.

1. Identification of people with possible dementia. Only about 20% of people with Alzheimer’s disease and other dementias have a diagnosis of the condition in their medical record. Planners recognized that increasing diagnostic evaluations required educating staff to recognize when an evaluation was needed. As a result, the model includes several lists of signs and symptoms of dementia for staff training. It also features a five-item questionnaire for family members who accompany the older person to the doctor’s office or clinic, since families often recognize the signs of dementia first. The questionnaire also conveys the message that the family’s ideas are important.

2. Diagnostic evaluation. This part of the model provides procedures for evaluating the person for dementia and gathering information needed for diagnosis and care planning. In addition to a medical examination, interview, and laboratory tests for the patient, the model includes a family interview and two questionnaires intended to elicit the family’s perception of the person’s functional status and information about family caregiver burden.

3. Blueprints for coordinated care. The model includes six blueprints that identify goals and approaches for coordinating medical and nonmedical care in three stages of a person’s illness. One blueprint addresses goals and approaches to involve and support family caregivers.

4. Programs and materials for family caregiver support. Project staff recognized that much information and many programs are available for family caregivers of people with dementia. Yet often, families do not have access to the right information or program when they need it. To improve the ability to link families with appropriate resources, the project needed a way to organize the materials and programs that were available in each of the sites. One possibility considered was categorizing the materials and programs according to the person’s stage of illness. Instead, however, planners decided to group them according to tasks the family faces in
six stages of caregiving and created grids to categorize resources for achieving key caregiver goals. Filling out the grids enabled the health care organizations and Alzheimer’s Association chapters to learn about each other’s materials and programs.

Over the past three years, the sites have been implementing the model and gathering data to evaluate outcomes. More than 1,200 people with dementia and about as many caregivers have been cared for using the model. Comprehensive quantitative and qualitative results of the project will be available in summer 2003. Preliminary findings and lessons learned include the following:

• The health care organization-Alzheimer’s disease chapter partnerships are working, but it takes time and a lot of patience. The model does not specify organizational responsibilities, so each partnership had to work that out for themselves. They have tried various ways of working together, and evaluation is expected to show what arrangements are most effective.

• Getting health care organizations to involve and support family caregivers is very difficult. The parts of the model that participating health care organizations used least related to caregivers.

To download the full model (40 pages), visit the National Chronic Care Consortium’s website at www.nccconline.org.
Signs of Progress: Increased Support for the Services Caregivers Need

Research: Caregiver Needs and Preferences

Results of the NFCA/NAC Caregiver Self-Identification Study

Gail Hunt, Executive Director, National Alliance for Caregiving  
Suzanne Mintz, President and Cofounder, National Family Caregivers Association

Results of a series of national focus groups provide important insights for organizations communicating with family caregivers. Conducted by the National Alliance for Caregiving (NAC) and the National Family Caregivers Association (NFCA), the research helps explain why many caregivers do not identify themselves as such and suggests the types of messages that will – and will not – resonate with them. NAC and NFCA will use this information to design a public education campaign that helps caregivers reach out for support.

The two organizations initiated this research because lack of caregiver self-identification has been a major barrier to reaching this audience with information and services. If you do not recognize yourself as a caregiver, you will not pick up materials targeted to caregivers or find service promotions relevant to you. NFCA/NAC’s hypothesis was that the term “caregiver” was simply unfamiliar to the public or might be confused with paid care providers.

In fact, however, the lack of identification with the term comes from the heart. People said that calling themselves a caregiver would change their relationship with the care recipient. Their more personal image is being a loving child/family member/friend or a loyal spouse.

Barriers in Caregiver Communication

The focus groups identified a number of barriers that communicators need to overcome to reach the caregiver audience:

- High stress levels. Caregivers are just too busy to identify their needs for help, much less find the resources to meet those needs. Effective messages about resources will do the work for caregivers, making services obviously relevant and easy to access.
- Unwillingness to focus on their own needs. Caregivers respond better to messages that emphasize the benefit to the care recipient than to “self-serving” appeals.
• Previous negative experiences with community service providers. Many reported calling agency-advertised numbers only to be sent on a frustrating series of calls to multiple organizations – often to find that services were not available to them anyway. Communicators will need to emphasize positive changes that have occurred since the National Family Caregiver Support Program and play up single-point-of-entry systems where they exist.

• Attitude that caregiving is a private matter. They do not want to talk about what goes on in the family, especially in the bedroom and the bathroom.

• Unwillingness to ask for help. Caregivers often feel that they are the only ones who can do the job right or they do not recognize that help could mean indirect but important assistance, such as mowing the lawn, watching the kids, or offering emotional support.

• Negative word connotations. Caregivers had strong negative reactions to the word “stress” and to any approach that cast them as “martyrs.” They also responded much better to the term “family caregiver” than to “caregiver” alone.

Caregiver Needs and Preferences

NFCA/NAC gave the focus group results to an advertising agency that develops public service announcements and had them test several message lines with caregivers.

The research also found that the sender of a message affected caregiver reactions. The most credible senders were other caregivers and nonprofit organizations.

The **Voices** Project: Understanding African American Caregivers of Chronically Ill Patients

Angela Heath, President, Heath & Company

The **Voices** Project, sponsored by the National Caucus and Center on Black Aged, conducted focus groups with unpaid African American caregivers of people ages 60 and older with at least one serious chronic illness, such as cancer, heart disease, arthritis, or diabetes. Designed to address the impact of cultural factors on African Americans’ approach to caregiving, the research identified knowledge and skill needs and cultural perceptions that can inform organizations developing programs for this population.
Knowledge and Skill Needs

Focus group participants said that they needed more disease-specific information to help them provide care at home. In particular they wanted more information about the following topics:

- Medication management. While caregivers said they got information about when and how to give medicines, they wanted to know more about drug interactions and possible side effects so they could address problems promptly and properly.
- Nutritional requirements. Caregivers needed more information on the dietary needs of their family members, such as how to balance a diet for someone with diabetes or how to read labels in shopping for low-fat foods.
- Warning signs that should prompt an immediate call to a health professional.
- All the treatment options available to their relative.

People in the focus groups also identified a unique set of skills that African American caregivers need:

- Advocacy with the health system and service providers.
- Recipe modification to suit cultural food preferences and health needs. This skill received special emphasis as a day-to-day, quality-of-life concern.
- Organization, to deal with the many health, financial, and personal needs of the care recipient.
- Partnership development with health and social services professionals. Participants stressed the need to create real partnerships in which both partners were equal and respected each other.

Cultural Issues

For African Americans, caring for family is a deeply ingrained value. In part, the bond with extended family, which most African Americans learn from childhood, underlies the expectation of family caregiving. While the impetus is also partly economic for those with lower incomes, nursing homes carry a social stigma and are usually viewed as a last resort only.

African Americans perceive that whites are less likely than African Americans to be family caregivers and less willing to make sacrifices to keep family members at home. While older people expect to receive care at home, they do not want to be a burden to their relatives. However, focus group participants worried that smaller families and geographic dispersion may erode the value placed on family caregiving. They noted that integration, which led to African American family members living in many different neighborhoods instead of near each other, has made family caregiving more difficult. Similarly, improved economic status has given some families more options. In the past, someone was always willing to take in an unmarried aunt or a widowed cousin, but today institutions seem to be a legitimate option.
In addition, the research found that participants were not aware of community services available to caregivers and had some negative perceptions about community agencies. For example, they felt that community agencies were less likely to inform African Americans about help they could receive. Many participants also resented the numerous questions social workers asked when they applied for services, viewing this practice as a form of discrimination.

Caregivers’ Recommendations to Health Care and Service Providers

Focus group participants made the following recommendations to improve support for African American caregivers.

- Provide computer training on how to use the Internet for information and services. Even though most participants did not own a computer, they saw electronic learning as the wave of the future.
- Train customer service representatives to work more effectively with caregivers. For example, teach them to address an older person with respect, using “Mr.” or “Ms.” rather than first names.
- Require health and social services professionals to listen to the voices of caregivers and show respect for the family as a unit, such as offering family counseling via conference call.
- Disseminate information on caregiver services through channels that reach African American audiences. For example, offer materials at employment agencies and promote resources through minority media.
- Use African American speakers in educational workshops for caregivers.
- Offer caregivers transportation to church, where they can receive social support and uplift their spirits.

Implications of the Voices Project

These research findings suggest that African Americans need more in-home, disease-specific, basic home health training to care for family members effectively and reduce their own stress. Healthy recipes for traditional foods would be welcomed. They also want the family defined as the client for centralized health and social services and to have forums to express their views to service providers. Given the lack of experience with nursing homes, tips on how the family can adjust to nursing home placement would help African Americans cope when and if this transition occurs.
The AARP Multicultural Survey: Exploring Diverse Caregivers and Their Needs
Elinor Ginzler, Campaign Manager for Independent Living/Long-Term Care/End-of-Life, AARP
Janet Lane, Senior Advisor for Communication, AARP

In the Middle, an AARP report on multicultural baby boomers coping with family and aging issues, presents the findings of a telephone survey of nearly 2400 Non-Hispanic White, African, Hispanic, and Asian Americans age 45 to 55 who had children under age 21 at home and parents/in-laws still living. Results show how this “sandwich generation” views their caregiving responsibilities and the impact of culture on perspectives and needs.

Overall, 87% of respondents said that family is the most important thing in their lives. While they admitted to stress, most felt that family was also a major source of strength. About three in four felt they were handling their responsibilities without too much stress, and they wanted to take care of their parents. However, two people in ten — and three in ten who said they had a heavy caregiving load — reported “extreme stress.” Nearly half of the total group felt they should be doing, or should have done, more for their parents, and even larger percentages of Asian Americans and Hispanic Americans held this view.

Those who felt the greatest burden reported having low incomes or poor health or being born outside the United States. The most common sources of support in coping with caregiver stress were faith and prayer, siblings, doctors, adult children, and other relatives. Very few cited government or employers.

Asian Americans

On average, Asian Americans were the most active caregivers (42% cared for elders personally or financially), yet about three in four said they felt they should do more for their parents. This is not surprising, since about the same proportion said that children in their culture are expected to care for elders. Paradoxically, more than two-thirds said they did not want their children to care for them when they got older – a theme that cut across all ethnicities. Asian American respondents also expressed more stress in their caregiving relationships than other races. One contributing factor is the large number of Asians who provide long-distance caregiving to relatives living continents away.

Hispanic Americans

Of the 34% of Hispanic American respondents who reported helping with financial support or personal care of older family members, half said they made a substantial commitment to hands-on care, such as providing home health care.
There was also a disconnect for this group between what they felt was expected of them (57% said that caring for older parents was the norm in their culture) and their own wishes (31% did not want their children to care for them).

**African Americans**

More than one in four African Americans reported caring for older parents while they were alive. This group had the highest incidence of life challenges, such as having lost both parents or been through illness or death in the family in the past year. About half said children are expected to care for parents, but about three in four do not want their children to care for them.

**Non-Hispanic Whites**

This group was the least likely to provide care for elders (19%) and to be sandwiched. About half feel they are expected to provide eldercare, but nearly four out of five do not want their children to care for them. Higher incomes and better health status characterized this population.

**Differences, but Also Commonalities**

The survey also found some gender differences in perspectives. For example, more women than men talk to doctors and arrange for aides. More women also report support from faith, prayer, and religious organizations and say that they feel closer to the care recipient because of caregiving. However, most of the differences in response by gender were less than 10%.

Overall, the survey showed that boomers are not as selfish or egocentric as their stereotype suggests. Across racial and ethnic groups, they are living up to their responsibilities, have a positive outlook on their role, and are coping fairly well. With the family as a major source of strength, they are squeezed by caregiving, but not excessively stressed.
Reaching Out to Caregivers: Innovative Approaches

Connecting Through Technology
Kathy Kelly, Executive Director, Family Caregiver Alliance

About 50% of Americans are now on line. Asian Americans are the most wired population, followed by Non-Hispanic Whites, Hispanics, and African Americans. The fastest growing segment of Internet use is among lower-income and lower-socioeconomic groups. As a result, the Internet already shapes family caregiver information gathering and will only grow in importance in the future. Internet and video technologies also provide interactive links with and among caregivers that improve services and reduce isolation.

The most common Internet resources for family caregivers are websites that provide information on and links to health and medical care, other relevant professionals, government/community services, and products caregivers use (see box).

Internet Resources for Family Caregivers

Some of the many valuable sites with high-quality information include the following:

- A directory of more than 2500 websites on aging, sorted by categories (http://www.aoa.dhhs.gov/agingsites/default.htm). This site is a good place to start a search for assistance, because its information is comprehensive and specific.

- Information on Medicare and Medicaid programs from the Centers for Medicare and Medicaid (http://www.cms.hhs.gov). The site includes regional contacts for out-of-state inquiries and Medicare Compare, an interactive database that helps consumers compare local plans. Another site with information on Medicare and nursing homes is http://medicare.gov.

- A National Council on Aging (NCOA) site (http://www.benefitscheckup.org/) offering the NCOA Benefits Check-up, which guides caregivers through questions and then identifies federal and state assistance programs for older Americans for which their families may qualify.

- Links to health information from agencies in the Department of Health and Human Services, including the National Institutes of Health (http://www.healthfinder.gov/).

- A clearinghouse that provides links to high-quality caregiving websites and reviews related educational materials (http://www.caregiving.org). The National Alliance for Caregiving operates this site.

- Information and contact information on about 4000 clinical trials, sponsored by the National Library of Medicine (http://www.clinicaltrials.gov).
In addition to websites, caregivers can find a variety of interactive on-line “communities,” such as on-line support groups, chat rooms, listservs, e-newsletters, and bulletin boards. These e-mail-based approaches allow people to share information and experiences with other caregivers facing similar situations, receive updates on topics of interest, and exchange social support.

Another application of computer technology is the telehealth consultation, in which caregivers have in-home access to health professionals via computer screen. This technology enables caregivers to ask questions, report concerns about the care recipient’s health, and feel more secure about their ability to manage the situation. The Veterans Administration alone reports about 350,000 telehealth consults per year.

The Family Caregiver Alliance is creating a new on-line resource for California caregivers, Link 2Care. A kind of an Intranet that links caregivers with their Caregiver Resource Center (see page 14), Link 2Care is tailored to the specific needs of individual caregivers, who fill out an on-line registration form. When complete, this technology will enable caregivers to have easy access to information sources they need, join on-line groups, learn about local events of interest, and be linked by video and on-line records to CRC professional assistance. Link 2Care is in its infancy now but will become an important adjunct to personal care services in the future.

Project ROSE: Reaching Out to Support Elders
Elaine Spain, Coordinator

Led by the Region Nine Area Agency on Aging (AAA), Project ROSE is a collaboration of nine agencies to provide respite care and other caregiver services to residents of 20 counties in rural Minnesota. This cooperative approach, which centralizes administration at the AAA, has expanded service provision, reduced administrative costs, and improved morale among the many small service providers on the project team. Other AAAs could adapt the Project ROSE model to their situations.

The Region Nine AAA, which already had established relationships with individual local nonprofit organizations, began to build collaborations by issuing a Request for Proposals for projects that would promote development of new or enhanced programs to support family caregivers. The RFP specified a preference for agencies and organizations working together and encouraged collaborations that spanned multiple counties or geographic areas. The agencies selected met to explore ways to partner with each other on a single project. Almost all were willing to work together but asked the AAA to take the lead because of its resources, expertise, and credibility.

Project ROSE now includes a wide variety of services to caregivers, many of which involve recruiting, training, and supervising volunteers who perform the services. In addition to
providing respite care, volunteers offer such help as shoveling snow, making friendly visits, grocery shopping, and cleaning house for caregivers. Another important service in this rural area is providing transportation.

This project has already realized significant benefits, including relieving local agencies of state reporting responsibilities, reducing the number of reports the state receives from twenty to one, and enabling local providers to spend more time working with caregivers (since they spend less time on administration). The partner groups also value the quarterly network meetings and a mentoring process that allows them to share resources, such as training materials and intake forms. An unexpected plus, the collaboration has become a support group for those providing caregiver support.

**Success Factors**

Several factors have been important in establishing and maintaining a successful partnership. These include:

- Building on existing relationships with local organizations.
- Allowing partners to retain their autonomy and identity in a flexible program model that recognizes their expertise in knowing what works for them.
- Requiring partners to meet AAA standards for the project.
- Conducting team-building with a core group of agencies, which now mentors new counties as they join the project.
- Increasing the visibility of respite care and caregiver services through strategic marketing.
- Having AAA take on the role of facilitator, administrator, and liaison, rather than being “in charge.”

In addition, *Project ROSE* moved slowly and anticipated a time-consuming process. By allowing team members to build on gradual accomplishments, partner organizations developed a “can-do” perspective and a sense of vision and excitement that continue to advance caregiver support.

**Faith in Action: Volunteers Helping Caregivers**

Sarah Cheney, Deputy Director, Faith in Action

Under the slogan, “A neighbor’s independence depends on you,” the *Faith in Action* (FIA) program enables volunteers to provide informal caregiving to people of all ages with chronic illness or disability. Coalitions of faith-based organizations partner with community agencies and civic groups to mobilize and train volunteers to help local residents in need. The services they provide, such as respite care, transportation, and help with home chores, benefit both patients and family caregivers.
Faith in Action began in 1983 when the Robert Wood Johnson Foundation (RWJ) offered grants for community demonstration programs to evaluate the potential of faith/civic group partnerships to help challenged neighbors continue to live in the community. The program funded 25 interfaith coalitions in 18 states and territories. The success of the first 25 sites, 20 of whose programs are still in operation today, led RWJ to fund a 1000-site replication program from 1993-1999 and a 2000-site effort that began in 2000.

The 1000-site program established FIA sites in all 50 states and three territories. The original grants provided $25,000 for 18 months with a one-year renewal option ($10,000). Today, about 80% of these programs continue their mission, and the coalitions that developed represent the religious makeup of the United States. On average, a coalition includes 19 faith groups and five community agencies. In addition to larger religious groups, such as Methodist, Catholic, Baptist, Lutheran, Presbyterian, Episcopal, African Methodist Episcopal, and Jewish, coalitions feature many faith-based organizations that are relatively small in the United States, such as Disciples of Christ, Baha’i, Unitarian Universalist, Hindu, Islam, and Seventh Day Adventist. Some larger coalitions have more than 100 member organizations.

Program Profile: Who is Involved? How do They Help?

Most volunteers in Faith in Action programs are women, especially those aged 31-49. They give more than three hours a week, even though most work full time. Retirees are the second largest age group represented. More than 50% of volunteers come from congregations in the coalition, although the program promotes volunteerism community wide.

While clients have included those from birth to age 100 and older, most volunteers help the elderly, primarily women over age 75. AIDS and other chronic diseases are the most common reason a person or family needs help. Most recipients are poor or very poor.

The services volunteers most often provide (about three per recipient on average) include transportation to a doctor’s office or pharmacy, respite care, and such household chores as meal preparation, bill-paying, shopping, and light housekeeping. Volunteers also help link their neighbors to other community resources they could use.

Expanding the Faith in Action Model: Lessons Learned

So far, close to 60,000 Faith in Action volunteers have helped more than 80,000 neighbors. The average budget for a local Faith in Action organization is $70,000 per year. This represents an average of 75 volunteers helping 140 neighbors at no cost to the client. In fact, priced at $12 per hour, FIA volunteer services are worth more than $104 million per year, and almost three programs in four say that no other agency in their community provides comparable free services.
The *Faith in Action* model has about an 80% success rate for project continuance after the initial grant, and caregivers are overwhelmingly positive about it. Experiences to date have produced valuable insights about how and why the programs work:

- The need is great and growing for the kinds of services FIA provides. *Faith in Action* receives thousands of requests, because people trust religious organizations enough to ask for help.
- An RWJ survey found that about three in four Americans were willing to help a friend or a nonrelative. More than 90% were more willing to volunteer for a program sponsored by a religious group than other types of organizations.
- Most religious organizations do not have the resources to sponsor volunteer programs on their own. The coalition concept increases the capacity of caring-oriented groups to capitalize on their commitment.
- Funders are more willing to support a coalition that includes many different faiths. This diversity bolsters a key program principle: that no religious group proselytize in the guise of volunteering.
- Successful programs need more than dollars. They also need technical assistance to build sustainable projects and community capacity, as well as a marketing/communication strategy that builds program identity and visibility.

RWJ’s support is helping to establish a national volunteer movement in which *Faith in Action* is part of the fabric of our communities. In 2000, the Foundation committed $100 million to bring *Faith in Action* to every community in America by 2007. Organizations that want to start FIA in their areas can apply to RWJ for support.

**Generations United: Increasing Caregiver Services for Grandparents Raising Grandchildren**

*Maggie Biscarr, MSW, Assistant Director, Generations United*

Generations United (GU) is the only national nonprofit membership organization whose sole mission is to promote intergenerational public policies and programs. One of its core initiatives is the National Center on Grandparents and Other Relatives Raising Children.

Since 1990, the number of grandparents who care for their grandchildren in their homes has grown by 30%. About 4.5 million children under 18 now live in homes headed by grandparents, and about one-third of them have no parent present in the home. While about 150,000 children are in the kinship foster care system, 14 times more children are being raised by family members outside the foster care system than inside – which saves the system billions of dollars. Although the majority of families in this situation are white, it occurs among all races and at all socioeconomic levels.
Grandparents with primary responsibility for care are 60% more likely to live in poverty than other grandparents. Most are ages 45 to 64, so they may also be caring for older parents. People often become primary caregivers for a grandchild because parents are not capable due to substance abuse, HIV/AIDS, death, incarceration, mental health problems, or lack of financial resources. Other common reasons include teen pregnancy, parental violence, abuse or neglect, and divorce.

**Grandparent Caregiver Needs**

Grandparent caregivers have many needs that are similar to those of other caregivers, but they also have unique legal problems that add to stress and financial burdens. Key issues include:

- Social and emotional impact of caring for grandchildren. Grandparent caregivers face emotional issues such as anger, resentment, grief, and loss regarding their child and insecurity/frustration in becoming a parent to a grandchild. Assuming this role also has social costs, including loss of friendships, marriage break-ups, and the stigma of having a child with “problems.”

- Health problems. Grandchildren in this situation have a high incidence of physical and mental health problems, and the caregiver’s own mental and physical health also often suffers. Adding to the concern, legal barriers often make it difficult to obtain health and dental insurance coverage for the grandchild. Respite and affordable child care are priority needs.

- Financial impact. The added costs of raising a child strain retirement savings and jeopardize financial security for many grandparents. While government subsidies may be available for some of those in poverty, middle income families who do not qualify for assistance are hard hit by the unexpected new expenses.

- Housing concerns. Grandparent-headed families have difficulty finding safe, affordable housing and often live in inadequate space. Particular problems occur for grandparents who had already moved into senior housing, are in public housing with limits on occupancy, or who lease other properties that do not allow children. In these cases, grandparents often try to hide the children, with resulting stresses and limitations.

- Legal concerns. Legal child custody is often needed to get services and benefits a child needs. Yet many grandparents cannot afford legal fees, and waits are long for subsidized legal aid services. In addition, mediation services often are needed to resolve disputes about a parent’s capability to care for a child and other issues.
Accessing Services Through the National Family Caregiver Support Program

In testimony before Congress, Generations United sought to have relatives raising grandchildren covered under the NFCSP, and the bill does include grandparents, step-grandparents, or other relatives by blood or marriage who are at least 60 years old, living with and primary caregiver for a child either informally or with legal status. However, only 10% of a state’s funding can be used to provide services to grandparents, and states are not required to provide any or all of these funds. State and local advocacy efforts will be needed to press for including the full 10%, and GU’s National Center for Grandparents and Other Relatives Raising Grandchildren has developed materials to support advocates. The materials include model programs showing how some AAAs are successfully providing needed services to grandparent caregivers.

With funding from a cooperative agreement with the Administration on Aging, GU’s National Center for Grandparents and Other Relatives Raising Grandchildren is also providing training and technical assistance to AAAs and State Units on Aging. The Center has developed a package of standard training materials and is now recruiting a national network of experts to provide training, using the materials and their own expertise. Issues covered include legal and policy issues, mental health issues, how to reach grandparents with information and referral services, respite care, support groups, and faith-based services. State and local agencies can fill out a request for training on line at www.gu.org.

**Strength for Caring: Training Family Caregivers of Cancer Patients**

Frances Barg, PhD, Medical Anthropologist/Instructor, University of Pennsylvania

*Strength for Caring* was developed at the University of Pennsylvania with funding from the Pennsylvania Department of Health, which recognized that training and support can help reduce the negative impact that caregiving can have on the health of caregivers. Thanks to funding from OrthoBiotech, the program is now available nationwide, with celebrity spokeswoman Cindy Crawford promoting it.

A six-hour program for small groups of caregivers of cancer patients, *Strength for Caring* is usually taught by a two-person team: a skilled group facilitator and a specialist in cancer care. They use modular training materials that can be tailored to individual family needs, including a detailed videotape that prepares trainers to lead the program, print materials, and slides. The package also includes guidelines and materials for promoting the program in the local press. It is available for free to hospitals, advocacy groups, and other community organizations.

*Strength for Caring* takes a family focus and addresses the different developmental needs different families may have. The program emphasizes the need to access community resources
and teaches information seeking as a coping skill for caregivers. In addition, it covers the cancer-related symptoms caregivers may encounter, patient and caregiver anxiety and depression, enhanced communication among family members through role play, and enhanced communication with the health care team, such as how to discuss pain constructively.

A *Strength for Caring* workshop usually has about eight to ten participants. It begins with an introduction to caregiving that validates caregivers’ needs as equal to patients’ needs. Each participant then discusses his/her particular questions and concerns to help the facilitators select topics to emphasize. Key issues family members typically raise are learning to prepare meals that are nutritious for cancer patients and meet their changing tastes; the stress of providing transportation to treatments; communicating with providers; helping with medication; and assessing the need for medication and treatment. As a result, much of the content is cancer-specific to allow family members to understand the disease and its treatments and how to alleviate patient medical symptoms and psychological and emotional issues like anxiety, body image, sexuality, and mental status changes.

Caregiver physical and mental health also receive attention. For example, a section on cancer and the family addresses psychosocial issues, normalizing the emotions family members have, such as anger, grief, loss of role, children’s concerns, spiritual issues, stress, and end-of-life issues (where appropriate). Objectives include helping caregivers learn how to avoid physical problems and recognize symptoms of their own that may need treatment, such as depression.

Longitudinal evaluation of more than 700 caregivers found that almost all participants felt more competent and confident in their caregiving ability after taking part in *Strength for Caring* than during the preprogram assessment. They also improved on measures such as self-esteem, ability to enlist other family members in caregiving tasks, identifying resources, physical health, quality of life, and levels of stress.

For more information or to find out about starting a program in your area, call 1-888-ICARE80 (Cindy Crawford will answer) or go to [www.strengthforcaring.com](http://www.strengthforcaring.com).

**Communicating Effectively with Health Professionals:**
*A Skill-Building Workshop for Family Caregivers*

Suzanne Mintz, President and Cofounder, National Family Caregivers Association

The ability of family caregivers to be an effective part of the health care team depends on communication. Health professionals often view caregivers as the people who are crying in the waiting room at an emotional time, not as potential partners in patient care. To be taken seriously, caregivers need the skills and confidence to facilitate information sharing and care coordination among an often multidisciplinary group of health care providers and advocate for their loved ones.
To assist caregivers in developing these skills, the National Family Caregivers Association and the National Alliance for Caregiving developed *Communicating Effectively with Health Professionals* (CEHP) in 2000. It has two components: 1) a three-hour caregivers workshop that includes a training manual and two caregiver workbooks (one for use during the session, the other a take-home resource with tools for talking to professionals and finding needed resources); and 2) a train-the-trainers workshop that trains interested individuals who make a commitment to go back to their communities and put on a caregiver workshop using CEHP materials.

The caregivers workshop includes five modules: introduction; communication, including barriers, suggestions to family caregivers, and the value of good communication; being part of the caregiving team, including members and their responsibilities, team dynamics, and outcomes; key principles of good communication, including a communication planner tool; and skill practice in office visit and emergency room situations.

Through use of the “Reader’s Theater Technique,” each module features the story of a caregiving couple, which triggers discussion of situations participants may encounter. Ideally, caregiver workshops include 12 to 18 people, which allows natural support groups and one-to-one friendships to develop.

NFCA received a grant from the Jacob and Valerie Langlaw Foundation to provide one train-the-trainer workshop for 50 people in March 2002, but more than three times that number applied. At the first workshop, trainers represented the Red Cross, AAAs, health systems, hospices, faith-based organizations and a variety of other health and service groups. Initial feedback was very positive, and the funder has agreed to support two additional train-the-trainers workshops. To obtain more information, visit [www.nfcacares.org](http://www.nfcacares.org).
Signs of Progress: Increased Support for Balancing Work and Family Commitments

Government Programs

Providing Paid Leave for Family Caregiving: Expanding the Family and Medical Leave Act
Renuka E. Raofield, Esq., Legal Counsel, Work and Family Programs, National Partnership for Women and Families

The Family and Medical Leave Act of 1993 (FMLA) guarantees covered employees 12 weeks of unpaid leave each year that they may use to care for newborn or newly adopted children, to care for seriously ill family members, or to recover from their own health problems. Because it provides only unpaid leave, however, it is a benefit that most workers cannot use. In fact, more than three in four employees say they have not taken needed family or medical leave because they could not afford to go without a paycheck to do so. Some who have taken the leave have been forced onto public assistance when salaries stopped.

The National Partnership for Women and Families is working to make family and medical leave affordable for all families by researching and promoting models that feature paid leave. Approaches used or proposed in new legislation in some states suggest feasible options. These include providing paid leave through the following mechanisms.

- Temporary disability insurance (TDI). New York, California, New Jersey, Rhode Island, Hawaii, and Puerto Rico have TDI systems or require employers to offer TDI, which provides partial wage replacement to employees who are temporarily disabled for medical reasons, including pregnancy and childbirth. Because it offers only partial salary, this approach can be affordable for employers. By expanding it to include time off for providing care to sick family members, states could make it possible for more workers to take advantage of FMLA.

- Flexible sick leave. At least 24 states have laws allowing public employees to use sick leave to care for certain sick family members, and at least three states (California, Minnesota, and Washington) require private employers to allow employees to use sick leave to care for sick children. One obstacle to this approach, however, is that many workers in the service industry, such as restaurant employees,
currently get no sick leave. Some states also have proposed to allow employees with sick leave to use it to attend a child’s educational activities and to contribute sick or annual leave to another employee who needs to take family leave.

- Unemployment insurance. Proposals in a variety of states suggest using this vehicle to fund leave for new parents and those caring for a seriously ill family member.

- Tax credits for employers. Colorado, Hawaii, and Missouri have proposed legislation to give tax credits to employers who provide paid family leave benefits.

- Direct funding. Proposals in a few states suggest allotting a portion of the state’s general fund to provide income for various types of employee medical leave; two states have proposed requiring matching funds from employers.

Most Americans (84%) support paid medical leave, and a Washington state study found that it would cost less than $40 per person, per year, to provide. Paid leave also has been shown to improve employee retention and productivity.

As advocates push for paid family medical leave, it is important to note that many employees are not even covered for unpaid leave through the FMLA, because they work for businesses with fewer than 50 employees. Advocates for caregivers seek to reduce this restriction to 25 employees.

**New Jersey’s Collaborative Model: Eldercare in the Workplace**

*Donna Wagner, PhD, Professor of Gerontology, Towson University*

Estimates suggest that New Jersey has more than 450,000 working caregivers. As many are under age 30 as between ages 55-60, and about half of them are men. The New Jersey state government partnered with county AAAs and New Jersey employers to create a statewide strategy for enhancing support to this sizable group. Funded by the Grotta Foundation, activities included research on employer needs and interests, an educational forum for the AAAs, and development of information resources. The project has led to enhanced dissemination of information on state resources for working caregivers.

**Employer Perspectives**

Only 7% of New Jersey employers surveyed reported that they had eldercare programs for their employees, and cost was seen as the major barrier to initiating them. Employers were interested in the concept, however, because of its potential to improve productivity, enhance employee recruitment and retention, and improve employee morale.
Before the collaboration, New Jersey employers had had little contact with the state’s Department of Health & Senior Services. Yet the majority wanted the state to provide information about community resources for elders, low- and no-cost eldercare programs, and working caregiver issues. About one-third felt that public/private partnerships were an appropriate way of addressing this need.

**Project Outcomes to Date**

The project is continuing to design a strategy to involve state and county agencies in assisting working caregivers and employers. The state aging network is now providing information about working caregivers and the resources available to them, and one AAA has hired dedicated staff just to address these issues. Staff are also disseminating a report on research results and recommendations and audiovisual tools for community agencies to use in making presentations to local businesses.

Although there was little history of cooperation between the business community and the state on caregiver issues, this project suggests that government can raise both the awareness and use of state caregiver resources through partnering with employers. This approach is low in cost, requiring only minimal staff time, and opens communication with a potentially important channel to family caregivers.

**Employer Programs**

**A Tool Kit to Help Employers Support Caregiving Employees**

Myrl Weinberg, CAE, President, National Health Council

Nationwide, only about 6% of employers offered comprehensive support for their caregiving employees in 1999. Yet caregiving is a growing issue for businesses, since 54% of the workforce will be caring for an older relative by 2008. According to the Family and Work Council, 37% of caregivers have reduced their work hours or taken off time to meet caregiving responsibilities, and some take early retirement or leave work permanently to provide care. This lack of balance between home and work duties costs employers $11.4 billion a year in lost productivity.

Caregiving also has many costs for motivated, hard-working employees. For example, employers may not offer—or employees may not be able to accept—promotions, training to acquire needed job skills, relocation/transfer, or some types of assignments that would interfere with caregiving. It is a daily challenge to fit caregiving responsibilities into a demanding work
schedule. While employees want to contribute to their employer’s success, simple logistical issues get in the way, such as the need to take a parent to a doctor’s appointment or make phone calls to service providers during work hours. In addition, the demands of caregiving at home can leave employees feeling tired, stressed, and distracted on the job.

If caregivers had the support and benefits they needed, they could achieve a positive work/family balance. Flexible jobs, employers that recognize the importance of caregiving, and assistance in learning about/accessing community services are some of the items employees say they need. In practical terms, this means:

- Flexible work hours.
- Job security.
- Financial assistance for caregiving, such as time off with pay or increased sick leave they can use for caregiving.
- Information to help prepare them for caregiving.
- Referral to caregiver support groups or counseling.
- A compassionate response to their situation from supervisors and colleagues.

A survey conducted by the Robert Wood Johnson Foundation’s Last Acts Workplace Task Force found employers recognize that supporting caregivers could improve employee satisfaction, morale, loyalty/commitment, productivity, and effectiveness. However, employers also have concerns that caregiver benefits might be very expensive and/or have a low cost-benefit ratio for the company. Human resources staff, who could advocate for caregiver-friendly policies, often have little experience or expertise in this area. Some are uncomfortable with getting the company involved in the personal lives of its employees.

**The Last Acts Workplace Tool Kit**

*Last Acts* is a national coalition of 943 organizations collaborating to improve care and caring at the end of life. Its Workplace Task Force advocates for supportive workplace policies, such as assistance for family caregivers. Following up on the survey discussed above, the task force asked employers what they needed to be more responsive to caregiving employees. Companies asked for an approach that would allow them to phase in benefits, successful models from other employers that they could replicate, and technical assistance in designing and implementing new programs.

In response, the task force developed a Workplace Tool Kit for employers, which contains materials to adapt, such as memos on a CD-ROM that employers could edit to meet their needs; guidance on relevant issues, such as changing corporate culture to place greater value on caregiving, assessing current benefits, and designing a caregiver support program; and model policies and benefits from which employers can pick and choose. Each topic also includes a special section offering low-cost options and other ideas targeted to small businesses.
In addition, the tool kit offers recommendations for employers who want to phase in caregiver benefits. This approach allows employers who cannot/prefer not to offer a comprehensive program at least to take some valuable first steps. The three levels of recommendations include the following suggested actions.

- **Low- or no-cost recommendations:** explain existing benefits; establish a sensitive, humanitarian environment; give caregivers educational materials; provide a list of local and national resources; and allow flexible work schedules.

- **Moderate-cost recommendations:** include caregiving materials in employee orientation packets; allow part-time schedules or job-sharing; allow leave time to accumulate and carry over; follow the FMLA in workplaces with less than 50 employees; develop or expand bereavement leave; and allow employees to pool their leave.

- **Higher-cost recommendations:** present seminars by experts on care options; train managers about appropriate responses and helpful company policies; refer employees to Employee Assistance Programs; increase the amount of sick time employees can use for caregiving.

Any company can begin supporting caregivers by reviewing its current policies and practices and making sure employees know the benefits the company already provides. Another simple step is to request and review the Workplace Tool Kit at www.lastacts.org.

**Easter Seals: Education and Adult Day Services for Working Caregivers**

Jed D. Johnson, MSW, MBA, Assistant Vice President, Adult and Senior Services
Lisa Reeves, MA, President and CEO, Easter Seals Washington, DC, and Maryland

In addition to providing services for the disabled, such as medical rehabilitation and job training, Easter Seals (ES) offers national and local programs that support working caregivers.

**National Programs**

Easter Seals operates 49 adult day services (ADS) centers around the country, serving about 2000 clients each day. In addition, ES offers two caregiver education programs that employers can hold for their employees:

- **The Eldercare Education Series.** Developed by the Winter Park Health Foundation, this four-hour, four-part program covers:
  - The parent-adult child relationship.
  - The health issues of aging.
- Caring near and far.
- Caring for the caregiver.

- Transportation Solutions for Caregivers. Developed under a grant from the Administration on Aging, this program features a videotape for caregivers about safely transporting a care recipient using their own vehicle. It also informs caregivers about resources available to modify their vehicles to adapt them safely for care recipients’ needs. In addition, the grant funds a telephone hot line and e-mail service for caregivers to ask transportation-related questions.

Partnering with Employers in Maryland

The Easter Seals Washington, DC/ Maryland office opened an adult day services center in the Baltimore area in 1997. The Centers for Medicare and Medicaid Services is next door, and the Social Security Administration (SSA) is a mile away; together they have about 17,000 employees. Prior to opening the ADS center, Easter Seals began collaborating with these two employers to make ADS available to their caregiving employees.

Working through the Employee Activities Association of both government agencies, ES has expanded its efforts in support of working caregivers to include:

- Surveying employees about their eldercare needs.
- Conducting monthly support groups for caregivers.
- Writing articles on caregiver issues for the CMS and SSA in-house publications.
- Creating a local videoconference on caregiver issues that was filmed and broadcast nationally to other employer sites.
- Participating in health fairs at the two workplaces.

This collaboration is a win-win situation for both ES and the two employers. ES has a known market for its services and CMS/SSA can link their employees to services that can improve productivity and retention.

Offering In-House Services to Caregiving Employees: The Johns Hopkins University WORKlife Program

Sandra Cobb, Program Manager, WORKlife Programs, Johns Hopkins University

The WORKlife Program at Johns Hopkins University in Baltimore, Maryland, offers employees information, consultation, and referral for child care, elder/adult dependent care, and for other issues blending personal and work life. Services for caregivers include confidential consultations and assistance for all stages of the caregiving process. Staff members trained in elder care
issues talk with employees about their individual situation and their questions and concerns. They can also recommend alternatives and options to assist employees in making decisions. About 150 employees use WORKlife’s eldercare/caregiver services each year.

WORKlife assists caregivers of older family members with information on:

- Choosing living arrangements.
- Medicare and Medicaid coverage.
- Local energy programs.
- Home equity and reverse mortgages.
- Disabilities and dementias.
- Health care advance directives.
- Home modifications for disabilities.
- Nutrition for older adults.
- Legal, financial, and health care decision making.

Information sharing also takes other forms, including educational workshops and lectures on aging and caregiving issues, a caregivers’ discussion group that meets monthly, and a collection of library books and pamphlets. Another important tool is the Milestones™ Elder Care Referral System. This database, developed and maintained by WORKlife, includes regional and national information on nursing homes, home care agencies, adult day care centers, assisted living facilities, elder law attorneys, retirement and continuing care communities, geriatric care managers, and AAAs.

While WORKlife began with only a child care focus, the goal was to meet all the work and family needs of employees. When program managers found that the average employee age was 46, they realized that eldercare and family caregiving would be growing concerns the program should include. Upper management, which believes WORKlife is valuable for employee recruitment and retention, supported the expansion despite added costs. Administratively, the program is funded by employee benefits.

While formal tracking systems to assess the impact of WORKlife on employee recruitment and retention are still under development, the stories of individual employees confirm the value of the program for caregivers. For example, one full-time employee is the primary caregiver for her mother, stepfather, and aunt, who all live alone in their own homes. Her mother is partially blind, has dementia, walks with a cane, and has had three strokes; her stepfather has Alzheimer’s disease; and her aunt is legally blind. The employee asked for advice on how to balance her work and caregiving responsibilities, which were negatively affecting her own health. Through WORKlife, she received referrals for community services and advice for gaining flexibility at work for the times she had to take off. With the program’s support and understanding, she has so far continued to work full time and provide care.

For more information, visit the WORKlife web site at www.hopkinsworklife.org.
Conclusion

Caregiving is Personal
Rosalynn Carter, Former First Lady, President of the Board, Rosalynn Carter Institute for Human Development

Caregiving touches us all. Either we have been caregivers, we are caregivers, we will be caregivers, or we will need caregivers. Because of rising life expectancies and the ability of medical science to prolong the lives of people who require long-term care, the need for caregivers is not going to go away.

I grew up with caregiving, and it has always been a part of my family life. When my mother’s mother died, my grandfather moved in with us, and I helped take care of him, along with a neighbor who looked in on him while my mother was at work. When my dad died, my mother had never paid a bill or dealt with practical household issues, and she relied on me. From the time she entered an assisted living facility (she refused to move in with us) until her death in 2000, I called or visited her every day. Never comfortable with Jimmy’s and my traveling, she always asked, “Where are you going next?” Now my brother, who recently had a stroke, is in a retirement home around the corner from our house. And every day when I visit, he asks, “Where are you going next?” So I’ve always known about family caregiving on a personal level, but I had not realized it was an issue for so many others until I founded the Rosalynn Carter Institute for Human Development (RCI).

The Rosalynn Carter Institute got involved in family caregiving indirectly, through our interest in mental health. We sponsored a conference on the burnout experienced by families caring for people with mental illnesses, and participants told us this was the first time anyone had understood or cared about what they were going through. Their emotional intensity told us we had stumbled on an issue of great need.

After the conference, we conducted a survey of family caregivers, and we found a sense of frustration, isolation, and loneliness. People told us that their friends only visited from a sense of duty and that everyone asked only about the care recipient, never about them. One woman said she “just wanted to run away,” and another one actually did check into a motel. Two hours later when she felt guilty and went back home, her husband was still in the same place, same position. We don’t prepare to be caregivers, but it is a responsibility we and our families shouldn’t have to face alone.

To help meet the need for quality, evidence-based programs to support family caregivers, the RCI established the National Quality Caregiving Coalition (NQCC). We took a collaborative approach, because it was a new field and we wanted to extend our reach to help as many as possible.
Today, the NQCC is involved in a variety of activities, such as our caregiver training course, *Caring for You, Caring for Me*, which many programs have adapted for use with their caregiver populations. I’ve written a book on family caregiving, and the RCI board has written *Caring and Competent Caregivers*. We have developed the CARE-NET model that integrates caregiver services by bringing together representatives of government, business, and religious organizations that often have never collaborated on anything before. This model is now being replicated in six Administration on Aging districts in Georgia. We also have a grant to develop a Community Caregiving Capacity Index to measure objectively what constitutes a quality caregiving community. With this index, we’ll next try to get every community in America to want to be a quality caregiving community.

Now that the role of family caregivers is widely recognized, there is strength in our numbers. The more we work together, the stronger we become. By advocating for policies such as Senator Clinton’s Lifespan Respite bill, we can continue to make a difference in caregivers’ lives.

References


Also Available From the National Health Council

**Family Caregiving Agenda for Action: 2001 Interim Report on Progress.** This report celebrates the substantial progress made and identifies the unmet needs of those who provide care for their loved ones. (November 2001) Available free on line at www.nationalhealthcouncil.org.

**300 Ways to Put Your Talent to Work in the Health Field.** An extensive guide to health careers, this book includes career descriptions, plus information on work setting, educational requirements, and salary for more than 300 careers. It also lists contact information for more than 150 organizations offering additional resources. (June 2002) 150 pages. Price: $15.00/members; $18.00/nonmembers.

**Health Groups in Washington.** This complete reference book is recognized as the single most useful resource for locating major nongovernmental health and health-related organizations in the Washington, DC, area. Contact information for more than 800 organizations. (August 2001) Price: $30.00/members; $40.00/nonmembers.

To order, go to www.nationalhealthcouncil.org to download an order form or call (202) 785-3910.