Family Caregiving:
State of the Art, Future Trends
March 6, 2007  •  Chicago, Illinois

Presented by
The National Center on Caregiving at Family Caregiver Alliance
In Partnership with The American Society on Aging

Sponsored by
The Jacob and Valeria Langeloth Foundation
The U.S. Administration on Aging
The John A. Hartford Foundation
The Caregivers Initiative, Johnson & Johnson
About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California’s statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Visit www.caregiver.org.

About The American Society on Aging

Founded in 1954, the American Society on Aging is an association of diverse individuals bound by a common goal: to support the commitment and enhance the knowledge and skills of those who seek to improve the quality of life of older adults and their families. The membership of ASA is a multidisciplinary array of professionals who are concerned with the physical, emotional, social, economic and spiritual aspects of aging. Visit www.asaging.org
Suggested Citation:

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Printed in the U.S.A
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Acknowledgements

The National Center on Caregiving at Family Caregiver Alliance (FCA) is deeply grateful to our conference partner and cohost, the American Society on Aging, who worked ably with us throughout the process of planning and presenting this conference. We also express sincere gratitude to our sponsors for their commitment to family caregivers and their financial support that made this conference possible: the Jacob and Valeria Langeloth Foundation, with additional assistance from the U.S. Administration on Aging, the John A. Hartford Foundation and the Caregivers Initiative at Johnson & Johnson.

These conference proceedings reflect a collaborative process involving many individuals and organizations. Our national planning committee provided invaluable assistance, dedication, guidance and expertise in designing all aspects of the family caregiving conference, from the workshop topics to the speaker invitations to the day’s schedule: Donna Benton, Jodi Cohn, Lynn Friss Feinberg, Nancy Giunta, Robyn Golden, Rick Greene, Jennie Chin Hansen, Gail Hunt, Kathleen Kelly, Mary Ellen Kullman, David Lindeman, Katie Maslow, Bryan Preston, Vicki Schmall, Cynthia Stuen, Jeanette Takamura, Paul Takayanagi and Carol Whitlatch. The 29 experts who accepted our invitation to moderate or to present their work at the various sessions and workshops deserve our deep appreciation. They shared their expertise, experience and diverse perspectives, and they inspired, informed and educated the nearly 250 conference attendees about the state of the art and future trends in family caregiving. Special thanks goes to Emily Friedman for offering a stimulating keynote address.

We thank the following FCA staff and consultants who made significant contributions to planning and implementing the one-day conference and to producing this final report: Cara Goldstein, conference logistics coordinator, with help from Amy Friedrich-Karnik, worked hard to ensure that the day ran smoothly and efficiently; Bonnie Lawrence and Leah Eskenazi offered support throughout the conference and in its preparation; Lana Sheridan and Kris Coffey arranged meetings and organized materials throughout the conference planning process; Beth Logan provided guidance and advice about the conference schedule; Melania Jusuf designed the layout of these conference proceedings, with editorial support from Evie Christou; and Carol Van Steenberg provided skilled editorial assistance throughout the writing of these proceedings.
Family Caregiving: State of the Art, Future Trends

Purpose and Overview of Conference

Although the surrounding circumstances have changed in the 21st Century, family and friends remain the primary source of care and support for adults with chronic illnesses or disabilities in the U.S. What is different now than in the past? How can we address the key challenges for family care in the decades ahead? The National Center on Caregiving at Family Caregiver Alliance (FCA), in partnership with the American Society on Aging (ASA), convened Family Caregiving: State of the Art, Future Trends to bring together key experts from practice, policy and research to consider these questions. (See Appendix A for Program Agenda).

The conference, which took place in Chicago on March 6, 2007, offered fresh perspectives on cutting edge research, explored effective service interventions and identified emerging issues that will profoundly affect family caregivers and those for whom they care. A National Planning Committee helped FCA design and conduct the conference. (See Acknowledgements for the names of committee members.) The Jacob and Valeria Langeloth Foundation, The U.S. Administration on Aging, the John A. Hartford Foundation, and The Caregivers Initiative, Johnson & Johnson, provided essential support.

In all, 271 individuals (see Appendix C) from 41 states in the U.S. and two countries (Israel and Japan) took part in the conference’s plenary sessions and breakout workshops, learning about promising practices and research trends pertinent to family caregiving. These proceedings aim to convey the key ideas and findings presented at the conference.

The organization of the proceedings reflects the organization of the conference. Following a summary of opening remarks from FCA’s Executive Director, Kathleen Kelly, is the keynote address by noted writer Emily Friedman and a summary of the morning’s plenary panel.
discussion, moderated by Columbia University's Jeanette Takamura, PhD. This panel featured Brenda Spillman, PhD, of the Urban Institute, Gregg Warshaw, MD, of the University of Cincinnati College of Medicine, Cindy Hounsell, JD, of the Women's Institute for a Secure Retirement, Carol Smith, RN, PhD, of the University of Kansas Medical Center and journalist Robert Rosenblatt.

The proceedings continue with a summary of all presentations made during the afternoon workshops:

- **Caregiver Assessment**, moderated by Katie Maslow, MSW, of the Alzheimer's Association, with presentations by Lynn Friss Feinberg, MSW, of FCA's National Center on Caregiving and Susan Reinhard, RN, PhD, now of AARP's Public Policy Institute.

- **Workforce Issues**, moderated by Nancy Giunta, MSW, John A. Hartford Doctoral Fellow at the University of California, Berkeley, with presentations by Robyn Stone, DrPH, of The American Association of Homes and Services for the Aging’s (AAHSA) Institute for the Future of Aging Services, Dorie Seavey, PhD, of the Paraprofessional Healthcare Institute and Gail Hunt of the National Alliance for Caregiving.

- **Caregiver Health**, moderated by Kathleen Kelly, MPA, FCA, with presentations by Richard Schulz, PhD, of the University of Pittsburgh and Erin DeFries, MPH, of the University of Florida.

- **Diverse Caregiver Populations**, moderated by Donna Benton, PhD, Los Angeles Caregiver Resource Center, with presentations by Carol Miller, of the National Center for Frontier Communities, Carmela Lacayo, of the Asociacion Nacional Pro Personas Mayores and Kimberly Acquaviva, PhD of George Washington University.

- **Leading Edge Caregiver Interventions**, moderated by Vicki Schmall, PhD, consultant in aging services, with presentations by Laura Gitlin, PhD, of Thomas Jefferson University, Mary Mittelman, DrPH, of New York University and Carol Whitlatch, PhD, of Benjamin Rose Institute.

- **Integration of Caregivers in the Health Care System**, moderated by Jodi Cohn, DrPH, of SCAN Health Plan, with presentations by Carol Levine of the United Hospital Fund, Jennifer Wolff, PhD, of Johns Hopkins University Medical Center and Adam Darkins, MD, of the Department of Veteran Affairs.

The proceedings conclude with a summary of recommendations put forth in the various sessions.
Conference Welcome

A 30-Year Partnership in Caring

Kathleen Kelly
Executive Director
Family Caregiver Alliance

Family Caregiver Alliance’s mission, since its founding, has remained the same: To improve the quality of life for families and caregivers through services, research, education and advocacy. FCA’s programs and services now operate on local, state (California) and national levels; daily hands-on experience with family caregivers grounds the effort. FCA, in its 30th Anniversary year, looks back at having served more than 50,000 caregivers—in their homes, in their communities and at a distance across the U.S.—often under very tough and stressful circumstances. FCA provides caregivers with practical information and support, and tested service interventions.

In 1977, a small group of concerned families and professionals in San Francisco joined together to develop the first program in the nation to recognize the needs of families caring for adults with cognitive impairment (e.g., Alzheimer’s disease, Parkinson’s disease, stroke, traumatic brain injury). FCA’s larger vision has been to advance the development of high quality, cost effective policies and programs in every state for caregivers. By pairing family stories with systematic data collection FCA aims to make systems change. FCA’s hope for this conference was that each participant gained a new perspective, fact or idea to help inform programs, policies and research and that each made new connections for information exchange, leading to new partnerships that build the caregiving movement in the U.S.
Keynote Address

The New Meaning of Caring: Forces Reshaping 21st Century Health Care

Emily Friedman
Independent Health Policy and Ethics Analyst

Tales from the front—the experiences of one’s own family and friends—reveal the real-life situation of caregiving:

• My stepmother suffered a stroke at the age of 75; my father, then 74, chose to be her primary caregiver. Carrying her for six years produced such stress on his back that within six months of her death he was confined to a wheelchair, in which he spent the last 10 years of his life.

• My friend Kelly, an only child and a single mother of two, had a flourishing career when it became obvious that her mother no longer could live independently. Kelly gave it all up to move to New Mexico to take care of her mom. She cared for her until she died, and is now is trying to establish a freelance career that allows her to take care of her children.

• Mary lives in Boston, her mother in Ohio. Despite having been very fortunate with her health, her mother, now in her nineties, is showing signs of confusion and serious neurological deterioration and therefore plans move in with Mary’s brother, who also lives in Ohio. Mary is wracked by guilt that she is not doing more to care for her mother.
Jack and Susie, native-born Hawaiians, live on Kauai. Jack’s mother moved to the mainland many, many years ago. She is no longer able to live independently. Jack and Susie, who have two children of their own, brought her to Kauai to an assisted living facility. The expense is so high that their sons’ future education is in doubt.

Dan and Winston live in Chicago. Winston’s mother, a cancer survivor, recently suffered a severe stroke. She had a strong desire to continue to live independently in Baltimore, her life-long home, but she could not. Dan and Winston brought her to an assisted living facility in Chicago. Now she is away from everyone and everything she has ever known. Despite the soft housing market, Dan and Winston managed to sell her home in Baltimore. That will pay for about six months of her care. After that they will have to go into their 401(k) retirement savings.

With one exception, the people in these stories are relatively young—in their forties or early fifties—so they have a very long road ahead of them.

Six forces are reshaping health care: demographic changes in our population; growth in public and patient consumerism; the changing structure of chronic disease and long-term care services; financing and coverage issues; health care policy and politics; and “wild cards” that blindside us even when we think we are prepared. These forces will provide a new and expanded meaning for caring and for caregiving.

**Forces Reshaping Health Care**

- Population Change
- Public and Patient Consumerism
- The Structure of Chronic Disease Services
- Financing and Coverage
- Politics and Policy
- Wild Cards

**Population Change.** The three major demographic changes pertinent to caregiving involve aging, women and diversity.

We are getting older as a society. In 2000, about 12 percent of the U.S. population was age 65 and older; by 2050, one in five (21%) will be 65 and older, and one in three Americans will be over 55. The youngest Boomer turns 43 this year.
Women will become a more pronounced majority, particularly in our oldest age groups. We will have a significant gender gap in terms of family caregiving. The majority of older men live with a spouse likely to be able to provide care; the majority of older women do not. Although more boys than girls are born, men tend to die earlier. By the time Americans are in their forties, it evens out; when we are in our sixties, women far outnumber men; and of those over 100 - our fastest growing population group - 80 percent are women. Men usually marry younger women, and older men are much more likely than older women to remarry. The result? In their later years, far more women than men live alone and in poverty. The implications for family caregiving are huge.

Diversity—racial, ethnic and religious—is growing. Places that have not had the experience of diversity before are beginning to feel it.

An older, predominantly female and far more diverse patient population will need formal support, but our workforce in health care is going to be much older, too. We are already seeing this pattern: the average age of staff nurses in the U.S. is 47. Whose scope of work, whose tasks and whose personal needs are going to be honored?

The system will have to adjust to these phenomena. We must learn to accommodate a much more diverse set of attitudes about aging, about disability, and about caregiving in a much more diverse society. We are going to see changing roles for women and men, sons and daughters; different patterns of acceptance or rejection of institutional care; and the desire for culturally and religiously sensitive caregiving. These are all hallmarks of how vulnerable people will want to be cared for in the future.

Public and Patient Consumerism. Rampant public and patient consumerism will rock health care. Consumerism is the product of many things, including fallout from the avalanche of corporate scandals, growing impatience with the paternalism of the traditional doctor-patient relationship, a far more knowledgeable patient population, the impact of the Internet and the strong desire for more self-determination in all aspects of care. The older patient today is not the passive, “compliant” patient of yesterday, but a much more informed, much more empowered, and much more self-determined person. This trend is likely to continue.

The Structure of Chronic Disease and Services. We will have more chronic illness for two basic reasons. One is aging; in advanced age, chronic conditions are almost inevitable. Equally important, over the past century we have learned to cure many acute diseases that used to kill people. The clinical portrait of older Americans shows that, in many cases, we have traded pneumonia in for Alzheimer’s disease. By mid-century (2050), 16 million Americans could have Alzheimer’s disease,
according to the Alzheimer’s Association. With more people facing disabilities and other compromises in their lives, the need for family caregiving will be even more acute.

The movement from institutional care to home- and community-based care continues. The good news is that more and more vulnerable people are living life on their own terms at home and in the community; the bad news is that this shift puts more responsibility onto family caregivers. We must advocate for greater home- and community-based care for vulnerable people because it is the right thing to do and not simply because it may be less expensive. But family caregivers must have the resources they need to do their job.

**Financing and Coverage.** Perhaps the most volatile area involving future caregiving is paying for it. Although everyone wants a solution, no one wants to pay. Health care costs overall and long-term care spending in particular continue to escalate; the impact on coverage of all kinds is profound.

Long-term care policy in the U.S. is based primarily on Medicaid, which finances about 47 percent of all such spending. Everyone who is dependent on Medicaid is vulnerable to funding cuts. Unlike Medicare, to which almost everyone over the age of 65 is universally entitled, as are certain persons with disabilities, Medicaid covers many of the most fragile people in our society, including beneficiaries of family caregiving. Medicaid eligibility varies greatly from state to state; recent cuts in several states have significantly reduced the numbers of people receiving Medicaid services.

Increases in premiums for private health care coverage continue to outstrip any increase in employee income. Rising premiums make it very hard for employers, especially small employers, to offer coverage. Currently, there are 46 million uninsured Americans, and another 15 to 30 million Americans whose insufficient coverage classifies them as underinsured.

The market for meaningful private long-term care insurance remains sluggish at best, beset by high costs, risk aversion by insurers and severe limitations in coverage. Less than 10 percent of people aged 65 and older have purchased private long-term care insurance.

Family caregivers often are in a precarious insurance situation themselves. At least 20 percent of family caregivers under the age of 65, the majority of whom are women, are uninsured; in many cases, they quit their jobs in order to provide care and could not obtain individual coverage. About half of family caregivers live in households with incomes below $50,000 a year and have a chronic condition themselves. It is very
difficult for them to purchase private coverage for either acute or long-term care.

For the foreseeable future, long-term care and chronic disease will continue to be paid for by Medicaid and out-of-pocket by families.

**Politics and Policy.** A deep ideological divide has opened up in Congress and in many state legislatures over the past 25 years. Fewer people are in the middle; many more are on the extreme ends. With such ideological rigidity and the resultant political gridlock, we can hardly expect to achieve reliable long-term Medicare and Medicaid funding for the chronically ill and for their family caregivers. Furthermore, health policy is very complex, with little consensus to guide policymakers. Until there is a groundswell of public insistence that something be done about health care costs, coverage and quality, many policymakers will be in a quandary as to what to do.

Also, the states and the federal government are in a constant tug-of-war when it comes to dealing with chronic care issues. The states pay a portion of Medicaid costs and the federal government pays the rest, which can be up to two-thirds of the total; on the other hand, the federal government pays for most of Medicare (beneficiaries contribute as well). Each side—federal and state—wants the other to provide all the funding, yet wishes to keep for itself all the policymaking power.

The one group that seems to be completely excluded is patients and their families, whose voices are rarely heard in health policy discussions.

But there are signs of hope in the policy arena. First, the Lifespan Respite Care Act (PL 109-442), when funded, will expand access to respite care, improve local coordination of respite services and help families obtain information on respite resources in their communities. Second, over the last ten years the proportion of spending for Medicaid beneficiaries receiving home and community-based services (HCBS) has increased steadily, providing more choice and more appropriate care than in the past. Today, over 35 percent of Medicaid long-term care expenditures are for HCBS. Third, California has enacted a comprehensive paid family leave program and at least eight other states are considering legislation supporting paid family and medical leave for workers to bond with a new child or to provide care for a seriously ill family member. Given the high overall cost to employers of employee caregiving—one study estimates the cost to be between $11.4 and $29 billion per year—other states are likely to take up the call to provide greater support for employed caregivers.
**Wild Cards.** Unexpected events can also profoundly affect health care. Some examples are natural disasters like Hurricane Katrina, an epidemic or pandemic of infectious disease (e.g., the so-called “bird flu”), technological breakthroughs that can transform our lives (e.g., the personal computer), a major shift in political alignments and priorities, or a public uprising (e.g., the civil rights movement in the 1960s).

**Caregivers and Advocacy.** Family caregivers and caregiver advocates can influence the forces that shape health care, especially long-term care. To do so, they should:

- Be aware of and knowledgeable about health policy in general and insurance coverage in particular, defining the landscape for themselves and not allowing others to say it is too complicated or to shut them out of public discourse.

- Understand that some things are inevitable, such as the aging of our society, and some are not. They should know the difference. One thing is not inevitable: Vulnerable people need not be left to an unhappy fate.

- Participate in the policy debate. We have every right, as well as an obligation, to participate. If we don’t put family and community care of the chronically ill on the health policy agenda, it’s unlikely that somebody is going to do it for us.

- Don’t just protest others’ ideas. Have reasonable alternatives if you want to make a change.

- Recognize that you’re not the only game in town. Caregivers are competing with other valid interest groups. Every other sector (e.g., housing, environment, military, economic development) also believes that its issues should be the highest policy priority.

- “Keep your eye on the prize.” Know what the prize is and pursue it, even if succeeding takes longer than we would wish. Any opportunity to make family caregivers an integral, properly compensated and supported part of our health care system is a win/win for us all.

The late New York Senator, Jacob Javits, spent his last years suffering from Amyotrophic Lateral Sclerosis (ALS). Near the end of his life, after years of encounters with the health care system, he said, “In health care, it strikes me that the issues are three: realism, dignity, and love.”
We must be realistic about the challenges we face in our own lives, in the structure of health care and in the policy arena. Our primary challenge is to respect the dignity of everyone for whom we care or for whom care should be available, no matter how difficult that can be. And whatever the policy obstacles, the ideological barriers, the insensitivities and fears of society and the crushing demands of our own lives, we have to continue to give the most singular, least understood, most meaningful and most powerful of all forms of caring, and that is love.

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Panel Presentation, Plenary Session

Family Caregiving: State of the Art, Future Trends
Moderator: Jeanette Takamura, PhD

- Research on Caregiving Patterns and Characteristics: Key Trends in Family Caregiving
  Brenda Spillman, PhD

- Health Care System Trends: Families as Care Partners
  Gregg Warshaw, MD

- Key Economic Trends: Baby Boomer Caregivers and Retirement Security
  Cindy Hounsell, JD

- Key Technology Trends: Care Management Tools
  Carol Smith, RN, PhD

- Key Media Trends: Caregiving in Popular Culture
  Robert Rosenblatt
Panel Presentation, Plenary Session

Family Caregiving: State of the Art, Future Trends

Moderator: Jeanette Takamura, PhD
Dean and Professor, School of Social Work
Columbia University

Research on Caregiving Patterns and Characteristics: Key Trends in Family Caregiving¹

Brenda Spillman, PhD
Senior Research Associate
Urban Institute

Informal caregivers—mostly very close family members, typically spouses and adult children—continue to be the foundation of long-term care for older persons in the U.S. Recent trends in the use of formal and informal care, however, indicate changing demands on family caregivers over time.

Between the mid-1980s and the mid-1990s several important things happened that affected the nature of informal caregiving. The number of family caregivers for chronically disabled elders went down. The reason, however, was a decline in the number of secondary informal caregivers.

There was no decline in the number of primary informal caregivers, but their efforts were more likely to be augmented by formal care provided by paid workers, in part because of dramatic increases in access to and use of Medicare home health benefits. This upward trend in formal care ended after payment system changes in the Balanced Budget Act of 1997 dramatically reduced the availability of Medicare home health care, particularly less skilled care from home health aides. These changes contributed to a dramatic decrease in formal care by 1999. As a result, by the end of the decade there had been a shift back to informal caregivers—most often a single family member—as the sole source of essential supportive services.

The National Long-Term Care Survey (NLTCS) is a nationally representative survey of Medicare beneficiaries age 65 and older designed to measure chronic disability and long term care arrangements. This analysis draws from four waves of Survey data for the years 1984, 1989, 1994 and 1999. “Disability” is defined as receiving help (including supervision) with or using assistive devices (e.g., canes, tub seats) to carry out one or more of six activities of daily living (ADLs), or one or more of eight instrumental activities of daily living (IADLs). Examples of ADLs are bathing, dressing or using the toilet. Examples of IADLs are shopping, meal preparation and managing money. “Chronic disability” is defined as lasting three months or longer.

Decline in Rate of Disability. Over the 15-year period studied, the rate of disability among older persons (age 65+) declined, with most of the decline occurring between 1984 and 1994. Despite the declining disability rate, however, the number of older persons with chronic disability rose, owing to the growth in the total number of older persons and the aging of the 65+ population. Families and long-term care resources in the community and in nursing homes thus faced greater demands, despite the disability rate declines.

Profile of Disabled Elders. Of the estimated 6.8 million older persons (age 65+) with chronic disability in 1999, about three out of four (76%) were age 75 and older, and more than half (51%) reported disability in at least three ADLs. The great majority had a spouse or adult child (85%).

Informal Care Use. Despite changes in patterns of formal and informal care use between 1984 and 1999, informal care was consistently the most common type of care. Throughout the 15 years, more than 90 percent of these disabled older persons received some informal care from family, either alone or in combination with formal, paid care.

Because of the substantial decline in formal care between 1994 and 1999, a greater share of chronically disabled older persons was relying entirely
on informal care from family and friends in 1999 than in 1994. This reversed the trend between 1984 and 1994, in which the use of informal help alone declined (from 69% to 57%); the use of both informal and formal care increased (from 26% to 36%); and the use of only formal care in the community also increased slightly (from 4% to 7%). Between 1994 and 1999, the share of older persons relying entirely on their family and other informal caregivers had risen to 66%, the proportion receiving both informal and formal care had declined to 26% and the share getting only formal care in the community again grew slightly to 9%. Older persons with the most severe disability level (five to six ADL deficits) had the largest decline in use of formal care, compensated entirely by increased use of only informal care, primarily provided by family members.
Spouse and Adult Child Care Providers. Among all older persons with chronic disability in the 1999 survey, 84 percent received some care from a spouse or child, 10 percent from other relatives only, and less than six percent from non-relatives only. The key factor in whether care is received from a spouse or child is whether the care recipient has these potential caregivers. In 1999, virtually all older persons who had a spouse received some assistance from this primary family member or an adult child (99%); among unmarried persons with adult children, the vast majority (86%) were receiving care from them. More than half (53%) of spouse caregivers were themselves age 75 and older. Adult children providing care were most commonly daughters, married and living with or near their parent. In 1999, more than four in 10 (43%) adult child caregivers were age 55 or older.

<table>
<thead>
<tr>
<th>Children Caregivers, 1999</th>
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<tbody>
<tr>
<td>Age of child</td>
</tr>
<tr>
<td>&lt;45</td>
</tr>
<tr>
<td>45-54</td>
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<tr>
<td>55-64</td>
</tr>
<tr>
<td>65+</td>
</tr>
<tr>
<td>Child is married</td>
</tr>
<tr>
<td>Child is recipient’s daughter</td>
</tr>
<tr>
<td>Distance to recipient</td>
</tr>
<tr>
<td>Resident</td>
</tr>
<tr>
<td>Less than 1 hour away</td>
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<tr>
<td>1-24 hours away</td>
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<tr>
<td>Child has children under 15</td>
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**(*) = change from 1994 is significant at the 5% (10%) level

The bottom line is clear: Family caregivers continue to provide the vast majority of the long-term care received by chronically disabled older persons in the U.S. There is no evidence of reduced family caregiving. Numbers of family caregivers have kept pace with increases in the numbers of older persons with disability. A larger share of older persons were receiving care from close family members (spouses or adult children) in 1999 than in 1994, and for those with the most severe level of disability, essentially the entire decline in the use of formal care between 1994 to 1999 was absorbed by family and other informal caregivers.

The impact for public policy and practice of these caregiving patterns and trends is of concern. First, the group of older persons living in the...
community with the highest level of disability—five to six ADLs—had the largest declines in formal care between 1994 and 1999. As a result, their family caregivers were more likely to be “going it alone.” Second, the age of family caregivers and the disability level of the recipients they are caring for continued to increase between 1994 and 1999. The implication is that caregiver burden and health risks are increasing, too, particularly for older spouses and those caring for highly disabled persons. Given the key role these family caregivers play in care for persons with chronic disability, policies that support and assist them may improve outcomes for both caregivers and care recipients.

Health Care System Trends: Families as Care Partners

Gregg Warshaw, MD
Professor of Geriatric Medicine & Family Medicine
University of Cincinnati College of Medicine

A result of the success of modern medicine is that many adults now live for many years with one or more chronic illnesses. The burden that chronic illness places on the individual, families, and society is significant. The health care system has been slow to adapt to the prevalence of chronic disease. The existing care system is complex and difficult for patients and caregivers to navigate. Fortunately, there are some new models of care that are working well in the community to help families in the care of their older relatives.

Chronic illnesses are commonly defined as conditions that last at least one year and require ongoing medical attention and/or limit activities of daily living (ADLs). Common chronic conditions include congestive heart failure, arthritis, diabetes, hearing and vision disorders, Alzheimer’s disease and related dementias, stroke and cancer. Chronic diseases and conditions, more common as we become older, may limit activity. As older persons accumulate more chronic illness they have more limitations in everyday activities. Living with chronic illness over many years can result in chronic pain, loss of function and independence, and increased reliance on family and close friends for support.

See the Fall 2006 issue of Generations, the journal of the American Society on Aging, edited by Dr. Gregg Warshaw and titled “Chronic Conditions in Later Life,” for a review of chronic illness in older adults and practice innovations.
Of particular interest is what happens when an older person has multiple chronic illnesses within our health care system. Older adults with multiple chronic illnesses (i.e., three, four or five or more chronic conditions) see, on average, eight to 14 different physicians, and make 15 to 37 physician-office visits a year. Family caregivers are often required to coordinate these complex care teams; at times an overwhelming task. Just driving the older adult to different physician offices and trying to schedule and coordinate different office visits is a tremendous challenge.

The complexity of today’s medical care system in the U.S. creates challenges and barriers that interfere with the ability of patients and their families to obtain optimal care. Health care providers are also frustrated by poor communication and excessive paperwork.

**Complexity of the Medical Care System**

- **Insurance Benefits**
- **Finding Quality Primary Care**
- **Communication with and Among Health Care Professionals**
- **Ethical and Legal Dilemmas**
- **Accessing Quality Palliative/Hospice Care**

**Insurance Benefits.** First, for example, although an important new benefit, the Medicare prescription drug benefit (Part D) is confusing for patients and their families, due to plan selection, medication tiers and
the premiums, deductibles, co-pays and the widely noted coverage gap known as the “donut hole.” Falling into the “donut hole”—the most criticized part of the Part D benefit—is beginning to be felt by many older people across the country.

Second, the managed care principles that we are trying to apply to Medicare with different options under Medicare Advantage (Part C), formerly known as Medicare + Choice, are extremely confusing to patients, families and providers. This has created an array of networks and benefit limitations that families and physicians really do not fully understand, creating challenges in making sure that people come to the right place with the right insurance. Much has changed since the days when older persons had a standard Medicare policy and benefits were relatively uniform. It is not unusual at all, today, for an older patient with Medicare to show up in the doctor’s office with an insurance plan that the physician does not participate in, creating frustration for everybody and delaying the delivery of needed care.

**Finding Quality Primary Care.** Primary care by a family physician or general internist is one way to help coordinate the team of 10 to 15 physicians that is part of the health care pattern for older people with multiple chronic illnesses. However, the future of primary care in the U.S. is now uncertain. The reimbursement system for physicians has shifted most of the resources to sub-specialty care, and the number of medical students interested in primary care is continuing to decline. Many primary care physicians work in stressed offices with less time to spend with each patient. High quality chronic disease management is nearly impossible to deliver in this busy and stressed setting.

**Communication.** Physicians vary in their ability to communicate well with patients and families, but they are especially poor in communicating with each other. The lack of integrated electronic health records (EMR) greatly increases the responsibility of family members to track, coordinate, and manage care. Team care is rare and there is not enough time to communicate with patients or caregivers. EMR systems are still rare in community practice across the U.S. An adequate and affordable EMR system that effectively communicates across different settings is urgently needed.

**Ethical and Legal Dilemmas.** A large part of primary care practice with older adults and their families is trying to understand the ethical and legal implications of the individual’s illnesses. Payment for long-term care is complex and limited. Advance directives (e.g., living wills, powers of attorney, guardianship) are oftentimes confusing and sometimes misleading. For example, in the nursing home, although much time is invested in reviewing “Do Not Resuscitate” (DNR) orders, most nursing facilities do not have adequately trained nursing staff or sufficient equipment to resuscitate pa-
What really is more important to the health team is to understand in more precise terms what type of care the older person wants: Would the patient like to go back to the hospital or be in an intensive care unit? Would they want to use antibiotics? Would they want a feeding tube? These more specific patient wishes do not always get addressed.

Finding Quality Palliative Care. The two terms “hospice care” and “palliative care” are starting to confuse families. “Hospice” generally provides support and care in the last phase of an incurable disease, focusing on both the person with the disease and their family members, so the person can live as comfortably as possible. The six-month life expectancy guideline to qualify for the Medicare hospice benefit also confuses families: When should their relative enter hospice? On the other hand, “palliative care” is an approach to care that aims to prevent and relieve suffering from a serious or life threatening illness and to support the best possible quality of life for patients and their families. Physicians remain reluctant to refer people into hospice programs or to palliative care teams. The expanding marketplace of for-profit hospice providers is generating increasing public awareness of these services.

Patient and Family-Centered Care. How can physicians, patients and their family caregivers interact more positively?

Core Concepts of Patient and Family/Caregiver Centered Care

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration

The core principles of patient and family-centered care are dignity and respect, information sharing, participation and collaboration. In some health settings these principles are beginning to be applied and interest in collaboration with family and in the entire care process is much greater.

New Models of Care. It is now understood by many health system experts that the system model with physician(s) as the “centerpiece” is not sufficient to manage chronic illness effectively, particularly multiple chronic illnesses in older people. It is essential to engage the patient and the family caregiver to understand the illness(es) and to encourage them to work with the physician to make the treatment plan work. Team care is essential. The best models with the most promising outcomes
are much less dependent on physicians and are more engaging of social workers, nurses, and nurse practitioners. However, in many communities, physicians are reluctant to change and it is a struggle to get the physicians’ “buy in” for these innovative systems of care.

In chronic care management, care transitions provide many challenges. Movement of patients from home, to hospital, to the nursing home, and then back home is poorly coordinated. Dr. Eric Coleman and his team at the University of Colorado have been leaders in an effort to empower patients and their families to take responsibility for the transmission of information during these care transitions. He has created a new team member: a “transitions coach” who meets with hospitalized patients and their families and helps them to understand their options in the community after discharge from the hospital. The coach then follows the individual to help with the transition from hospital to home, putting emphasis on the family caregiver’s responsibility for ensuring a good transition. Education of the patient and caregiver and partnership as part of the care team are the keys. Often, we underestimate the caregiver’s potential to improve the outcomes in chronic illness.

**Changing Behaviors.** Physicians need to follow several behaviors to make patient and family-centered care work: Including the caregiver or advocate in the appointment; encouraging patients and their caregivers to ask questions and participate in problem solving; providing information on community services; and taking time and following through with both the patient and family. We also need to encourage some behaviors of our families and caregivers. These include: Making a list of questions for the physician prior to the appointment; understanding the patient’s health insurance coverage; working with the health care provider to learn the best treatments for the patient’s illness; maintaining a personal medical summary record; and being specific about what treatments the patient wants or does not want from the health care provider.

**Conclusion.** The medical care system today is overly complex. As discussed, Medicare Part D as designed and implemented is too complicated for patients and caregivers—and impossible for physicians to understand. Chronic disease is now predominant in medical care practice in the U.S., and traditional models of care are not effective for managing chronic illness. Most of the new, more effective models of chronic care management involve patients and their families to a much greater degree. Changing the health care system in the U.S. is very difficult and occurs very slowly. We will all need to be patient as we continue to advocate for families as care partners.
Key Economic Trends: Baby Boomer Caregivers and Retirement Security

Cindy Hounsell, JD
President, Women’s Institute for a Secure Retirement (WISER)

Retirees’ basic needs are income, medical coverage, prescription drugs, and long-term care. However, not having the first one, income, compromises getting the others. Retirees say two things: “I never realized that I would live that long,” and “I wish I had saved more and paid more attention to financial issues.”

Where do we get sources of retirement income? A few decades ago people used to talk about the three-legged stool of Social Security, pensions and savings. Today’s reality is a five-legged stool: Social Security, pensions, savings/investments, earnings from work and Supplemental Security Income (SSI). Working for income is now taken for granted. We’re all going to have to work as we get older, because people just do not have enough money. Only half of the work force has access to any type of retirement plan today. The median amount of money that people age 55 to 65—those individuals closest to traditional retirement age—have today in retirement assets is only $88,000, and that is actually up from five years ago.

Women and Retirement Income. Women generally need more retirement income than men for a variety of reasons. Women live longer than men on average and therefore need more money to cover all those additional years. Those fortunate enough to live until old age are likely to have at least one chronic illness. In addition to longevity and outliving assets, retirement risks include changes in family structure, unexpected health care needs and costs, loss of the ability to live independently; and lack of available care facilities or caregivers.

<table>
<thead>
<tr>
<th>Why Women Need More Retirement Income</th>
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<tbody>
<tr>
<td>• Women live longer.</td>
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<tr>
<td>• Women are more likely to need long-term institutional care.</td>
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<tr>
<td>• Women are more likely than men to be single and not remarry.</td>
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<tr>
<td>• Almost one-fourth (23.6%) of women age 65 and over who are alone live below the poverty level.</td>
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<tr>
<td>• Women are less likely to be able to afford to leave the work force due to need for income.</td>
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Caregivers and Poverty. Research shows that women who assume caregiving responsibilities face serious economic consequences. A Rice University study found that middle-aged women (aged 51 to 61 years) who assumed caregiving roles for their aging parents were 2.5 times more likely than non-caregivers to end up living in poverty; they were five times more likely to receive public assistance through SSI when they were older themselves. Single women caregivers had an even higher risk: They were four times more likely than married caregivers to live in poverty in later life.

Caregiving Costs Dearly. Obvious examples of the costs of caregiving are loss of salary and benefits due to quitting a job to give care; loss of pay from reducing hours on the job or working part-time; loss of promotion opportunities that require more hours on the job; and loss of training opportunities that require travel. Among the less obvious examples of the economic impact of caregiving are reductions in savings and investments; lost opportunities for compound returns or 401(k) matching contributions; and an inability to finance home improvements that could increase the resale value of a home.

Family caregivers who are considering leaving their job or reducing hours to take over caregiving responsibilities should first consider several questions and financial steps:

1) Will you receive less from Social Security benefits? (Social Security uses your best 35 years of work to calculate your benefit; zeros are added for fewer years.)

2) How will leaving the labor force affect your retirement plan? Are you "vested" with your agency or company? (It usually takes three to six years to be vested and able to receive retirement benefits.)

3) Do you have disability insurance and health insurance if you are hurt or become ill?

4) Have you considered how difficult it may be to re-enter the workforce when your caregiving responsibilities end?

Women caregivers commonly make a variety of money mistakes. Based on the personal experiences of women across the country, frequent mistakes include: Not making their own finances a priority; using their own money for the care receiver’s everyday expenses, such as grocery store and drugstore purchases; trying to pay more than they can afford, not realizing that they may end up living on their own some day; and not saving for retirement because they are busy helping everyone else first—especially children and grandchildren. Ms. Hounsell explained that she...
compiled this list of common money mistakes from listening to women across the country who have shared their experiences.

Two directions for policy change are clear. First, promote an integrated retirement policy that covers Social Security, employer retirement plans, savings and long-term care. The U.S. has never had an integrated retirement policy. As a result, many people fall between the cracks and cannot make ends meet in old age. When Congress makes changes in pensions, the implications for savings policy or Social Security are rarely considered. Second, when it comes to saving for retirement, government needs to understand the limits on individual action. Yes, everybody can save, but not everybody can save enough.

Key Technology Trends: Care Management Tools

Carol Smith, RN, PhD
Professor, University of Kansas Medical Center

Rural areas have a higher proportion of older people and fewer health care and social service providers. Consequently, rural elderly rely even more on family and friends for assistance than their peers in the cities or suburbs. Some care management tools are transforming the way families manage chronic illness at home especially in rural communities. These tools include high-tech home health care, Web-based communication and assistive technology.

Preparedness is one of the most important elements for success in managing care at home and improving the quality of life for both the caregiver and the person receiving care. Crucial information about how to care for a loved one in the home, support, respite care and mental health services all can be provided by technology. Not only may this approach be simpler and less costly than traditional means, it also may lead to greater improvements in the quality of life of family caregivers and better support for the patient as well, including slowing decline.

An example of the use of technology in the home is the information interaction station. Such a computer-based station has a simple touch screen that caregivers can use to get information and video guides, short
lists of problem solving techniques, and access to experts to help manage care in the home and to other family members for problem solving.

Caregivers benefit greatly from assistance with problem solving. Research has shown that a short list of problem-solving topics (e.g., how to deal with pressure ulcers, how to get insurance together, how to talk to your physician) can be placed in small, easily read, fifth grade level problem-solving algorithms that the caregiver can use to manage their care situation better.

Internet-Based Solutions. Web-based tools have been tested to guide decision making. The most widely used system is the Comprehensive Health Enhancement Support System (CHESS), developed by researchers at the University of Wisconsin. CHESS has been extensively studied and has positive outcomes in almost all populations studied (e.g., breast cancer, prostate cancer, heart disease, dementia caregiving), resulting in increased information, interaction and support.

In 1999 Family Caregiver Alliance adapted and tested CHESS with family caregivers of persons with dementia. Entitled Link2Care, this program is now an online resource for caregivers who are clients of California’s Caregiver Resource Centers (CRCs). Link2Care provides caregivers with information, emotional support and tools for decision making. Through Link2Care, caregivers may access a library of fact sheets, articles and links to other websites; a peer-moderated support group where caregivers can problem-solve with one another; “Ask the Expert” to obtain personal consultation with technical experts in caregiving, law and health; personal online journaling; and current caregiver news and topics. Link2Care and CHESS results, from across the U.S. and across health conditions, show that caregivers gain an increased sense of social support; increased emotional strength; decreased depression; continuing ability to problem-solve and manage care at home; more information to help their loved one; and more support for themselves. The most notable finding has been that these outcomes occur across socioeconomic groups.

Telephone-Based Help. Simple technologies like the telephone have been widely used to inform and support caregivers by offering peer support groups and education and training workshops. Recorded information can be sent to caregivers’ telephones and caregivers can take part in videoconferences, using existing telemedicine and educational technology infrastructures.

Home Telehealth. Today, telehealth is changing the way we think about the delivery of health care over distance in the U.S. Telehealth is a broad term that includes the use of health telecommunication, information technology and health education to improve the efficiency and quality of
health care. Consider one example, the “picture phone.” This small device is mailed to the patient’s home and plugs into their telephone jack. Using its small screen, the patient or family member can see the nurse or social worker who is providing counseling or demonstrating specific tasks (such as how to do a tube feeding). It also can be used in monitoring health conditions (e.g., wound care). The health care provider can have the family member move the camera up close to a bed sore, enabling the provider to make a measurement of it and see if it is changing. With that information, the provider can give the family caregiver some ideas on ways to reduce the problem. Family caregivers have high satisfaction with home telehealth. They like to telephone their “TV nurse,” as we are called. Studies have found this technology reduces the cost of home health visits by 33 percent.

Some of the more sophisticated telehealth devices allow the nurse to listen to the lungs of a patient, take oxygen measurements and complete other health screens. In a rural area, such devices enable a nurse to see some families three or four times a day—far more frequently than it would be possible to conduct in-person visits.

*Disease state monitoring systems* are similar devices that transmit data to automated base stations that, in turn, send alerts to patients and providers about oxygen levels and changes in blood pressure. This information has the potential to help avoid strokes or other conditions. The biggest concern about these automated patient-monitoring devices is the ethics of surveillance. Other ethical concerns include the potential for isolation and depression, whether distance care is inhumane due to the lack of a physical presence of a care professional, and whether or not there will be universal access to these devices.

**Other Assist Devices.** *Automatic medication dispensers* help remind people to take their pills. These dispensers can be particularly beneficial to the people with multiple chronic illnesses who see many different physicians each year and are prescribed many different medications. Keeping multiple medications on track is oftentimes a daunting challenge for a family caregiver, and some caregivers find these dispensers to be very useful. *Vibrating alarm watches* use ultrasound to get blood glucose readings and alert the caregiver when the patient is having difficulties with their oxygen level.

Another useful technology is the *music CD for 10-minute naps.* This CD has been tested in the sleep labs and in homes with caregivers. It plays music with a cadence that can get someone quickly into REM sleep for a 10-minute nap. Caregivers are very fatigued. A 10-minute nap—enough time to get some rest but not disrupt sleep patterns—has been shown to make family caregivers more alert and have better judgments in carrying out tasks, as well as to lower emotional strain somewhat.
Other assistive devices also can make life easier and aid people with disabilities and their caregivers in carrying out everyday activities. *Scooters* help people to get around and *lifting systems* may relieve caregivers of the physical strain on their backs from lifting and transferring a person from bed to chair.

While not in wide use, emerging technologies offer glimpses into the future. The University of Washington has designed what they call an *activity compass*. This device offers assisted cognition for Alzheimer’s patients; reducing disorientation can benefit both the patient and caregiver. *Robotic assistants* are on the horizon too. Research has shown that the use of robots can reduce anxiety and combative behavior in people with dementia. In Japan, robots are in all nursing homes, helping with medication administration and different types of socialization. *Individual and Smart House devices*, designed for automated patient monitoring through motion sensors in doors, windows or cabinets and sometimes with microphones and cameras, can be of particular benefit to long-distance caregivers.

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**Key Media Trends: Caregiving in Popular Culture**

Robert Rosenblatt  
Journalist, Washington, D.C.

Family care advocates, practitioners and researchers can get their message across in the media in a more effective way. A caregiving story, done right, can be very powerful. But it is very hard to get a message across today because the collective attention span has gotten shorter and will be getting even shorter in the future. From the point of view of the media, those who work with family caregivers are just another “pressure group”—a group with a compelling story, but, nevertheless, a group that wants its share of resources, attention and legislation.

**Call to Action.** Often, caregiving stories can be heartwrenching—describing how family members spend every day, 24 hours a day, taking care of a loved one, with no time off. They help with everything from bathing to eating, to administering medications, to going to the doctor’s office. However, focusing on the extreme stories often make people nervous. What makes a story more effective is to pose solutions and put forth a call to action.
An example of good reporting is a two-part series done in 2006 by Susan Dentzer, an on-air correspondent with *The NewsHour with Jim Lehrer* on the Public Broadcasting Service (PBS). This series examined our current understanding of the causes of Alzheimer’s disease, efforts under way to speed treatments to patients, and the enormous burden faced by the family caregivers of persons with Alzheimer’s disease. The caregiver story focused on former TV journalist Meryl Comer. Her husband, Harvey Gralnick, a former physician and scientist with the National Institutes of Health (NIH), had suffered from Alzheimer’s for over a decade. Research funding for Alzheimer’s disease in the NIH budget is decreasing at the same time that the number of people with the devastating disease is increasing, the segment pointed out. While providing compelling information about the everyday challenges faced by Mrs. Comer in the care of her husband, the story also enabled the viewer to take action: Call your Representative and say we want the NIH budget for Alzheimer’s research increased, not decreased.

**Media Appeal.** Many media outlets picked up a press release from the University of Southern California’s Longitudinal Study of Generations about the publication of a recent study with some encouraging news about family care. The main finding of this research is that the generation born in the 1950s and 60s is more committed to caring for their aging parents than were their own parents. By providing important evidence of the resilience of families, this study suggests that—contrary to popular belief—families are still able to instill strong attitudes about familial responsibilities. Despite shrinking family size (fewer adult children) and changing family dynamics (e.g., increased divorce rates, more women in the labor force), the message is that adult children are highly committed to caring for an aging parent. However, increasing burdens and costs of care likely will fall on fewer family caregivers in the future.

Tie caregiving concerns to issues of current interest to the media. For example, media attention now is focused on covering basic health care for the uninsured. In the campaigns to cover the uninsured, discussions of long-term care are conspicuously absent. Caregiving advocates should be raising questions about coverage for long-term care in these debates at the federal and state levels. Health care reform with no mention of long-term care means long-term care will not be addressed for many years to come. Another issue in the media of importance to caregivers is immigration. Due to the severe nursing shortage in the U.S., nurses are now coming from the Philippines, India, and more recently, South Africa. The direct care workforce increasingly will be immigrants. Reporters will want to know your position, as a caregiving advocate, on immigration.

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Communication Tips. When you are dealing with reporters and the media, keep some things in mind that will facilitate communication with them. It is all about the Internet now. One reason that reporters have less time these days is that not only do they write for the newspaper but they have to write for its website, too. To be effective with the media, you have to have a website that works, is easy to navigate and provides the ability to communicate with the general public as well as reporters. You should be able to summarize what your organization does in one page, and you should provide a telephone number where you can be reached during the day and after hours, as well as your e-mail address.

Finally, if you are at an event and see a reporter that you want to cover your story, do not buttonhole the reporter. On the back of your business card write in two sentences why you have a compelling story and give it to the reporter. If your two sentences are good, the reporter might just contact you.
Concurrent Workshops

Promising Practices & Research Trends

- **Caregiver Assessment:**
  Filling the Gap in Policy and Practice
  Moderator: Katie Maslow, MSW
  Presenters: Lynn Friss Feinberg, MSW
  Susan Reinhard, RN, PhD

- **Workforce Issues:**
  The Link Between the Informal and Formal Care Networks
  Moderator: Nancy Giunta, MSW
  Presenters: Robyn Stone, DrPH
  Gail Hunt
  Dorie Seavey, PhD

- **Caregiver Health:**
  The Link Between Prolonged Stress and Illness
  Moderator: Kathleen Kelly, MPA
  Presenters: Richard Schulz, PhD
  Erin DeFries, MPH

- **Diverse Caregiving Populations**
  Moderator: Donna Benton, PhD
  Presenters: Carol Miller, MPH
  Carmela Lacayo
  Kimberly D. Acquaviva, PhD, MSW

- **Leading Edge Caregiver Interventions**
  Moderator: Vicki Schmall, PhD
  Presenters: Laura Gitlin, PhD
  Mary Mittelman, DrPH
  Carol Whitlatch, PhD

- **Integration of Caregivers in the Health Care System**
  Moderator: Jodi Cohn, DrPH
  Presenters: Carol Levine
  Jennifer Wolff, PhD
  Adam Darkins, MD
Concurrent Workshops: Promising Practices and Research Trends

Caregiver Assessment: Filling the Gap in Policy and Practice

Moderator: Katie Maslow, MSW
Associate Director, Alzheimer’s Association

Strengthening Families: Forging Consensus on Caregiver Assessment

Lynn Friss Feinberg, MSW
Deputy Director, National Center on Caregiving
Family Caregiver Alliance

For over 44 million Americans, the challenges and pressures of family caregiving are a reality of daily life. Today, family caregivers monitor chronic and sometimes acute medical conditions as well as provide long-term care at home. Although family and friends are the backbone of our health and long-term care system, the significance of their role, and their own care-related strain and compromised health, is often overlooked. A 25-year body of research shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk. Emotional, physical and financial problems arise from the complexities and strains of caring for frail or disabled relatives, especially when the care is for a person with dementia. These burdens and health risks can
impede the caregiver’s ability to provide care, lead to higher health care costs, and affect their quality of life and those for whom they care.

**Caregiver Assessment and Its Importance.** Assessment has long been seen as a critical step in determining appropriate support services. “Caregiver assessment” is a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on help the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver’s own health and well-being.

The policy direction in the U.S. toward more home and community-based care as an alternative to institutional care depends greatly on family caregiving. Practitioners must consider not only how the family caregiver can help the care recipient, but how the service provider must help the family. The success of most care plans—from hospital discharge to home—often rests on the family caregiver’s shoulders. If the family caregiver becomes sick or can no longer cope with caregiving tasks, the care recipient suffers. If the strain on a caregiver becomes too great, care in the home may be seriously compromised and can lead to nursing home placement. Therefore, effective outcomes in care settings (e.g., hospitals, home, community-based care) depend upon knowing the needs and risks of both the care recipient and the family caregiver. Because serious illness and chronic disability affect the family too, a person- and family-centered perspective is essential for quality improvement in the redesign of long-term care systems.

**Myths and Realities.** Resource restrictions (e.g., not enough staff, hours or funding) may influence an agency’s response to caregivers’ needs, but much depends on how family caregivers are viewed in general. *Are family members seen merely as “resources” to the care recipient or as people with needs and rights of their own?* Commonly held misperceptions often stand in the way of recognizing, understanding and meeting caregivers’ needs.

**National Consensus Development Conference for Caregiver Assessment.** In September 2005, the National Center on Caregiving at Family Caregiver Alliance convened the National Consensus Development Conference for Caregiver Assessment. It had two goals: (1) generate principles and guidelines for caregiver assessment; and (2) build common ground among leaders committed to innovation and the systematic generation of new knowledge.4

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4 The Robert Wood Johnson Foundation provided primary support for this conference with additional support from the Archstone Foundation and The California Endowment.
The consensus conference brought together 54 widely recognized leaders in health and long-term care, with a variety of perspectives and expertise, to advance policy and practice on behalf of family caregivers. Through the consensus development process, the conference achieved recognition of the importance of systematically assessing a caregiver’s own needs in health care and home and community-based settings; articulated agreement on seven basic principles to guide policy and practice based on scientific evidence, clinical experience and expert opinion; identified change strategies to advance caregiver assessment as a basic component of practice; and heightened interest among the invited leaders to take steps to promote caregiver assessment.

**Moving Forward.** The National Consensus Conference resulted in several final products; all are available online at [www.caregiver.org](http://www.caregiver.org). The National Guidelines Clearinghouse (NGC) has also accepted the consensus principles and practice guidelines and posted them online at: [http://www.caregiver.org](http://www.caregiver.org)
Family Caregiving: State of the Art, Future Trends


Systematic caregiver assessment practices are both desirable and feasible as part of the broader health care and long-term care system. However, adoption of these consensus principles requires a fundamental change of thinking in policy and practice, one embracing a family-centered perspective.

### Fundamental Principles for Caregiver Assessment

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address their needs.

2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.

3. Caregiver assessment should result in a care plan (developed collaboratively with the caregiver), that indicates the provision of services and intended measurable outcomes.

4. Caregiver assessment should be multidimensional in approach and periodically updated.

5. Caregiver assessment should reflect culturally competent practice.

6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners and service providers’ education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.

7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

Policy Changes to Promote Caregiver Assessment

Susan Reinhard, RN, PhD
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Rutgers University

As national awareness of the crucial role that family caregivers play in health and long-term care grows, so does interest in assessing their needs. A major shift has occurred over the past decade and family caregiver assessment is now clearly on the public policy agenda. But how do we move from “beginning interest” about caregiver needs in home and community-based publicly funded programs to full-scale, systematic inclusion?

Policy Goals. Family caregivers can be seen as both clients and providers; each view has public policy implications. First, caregivers are sometimes referred to as “secondary patients” who need and deserve protection and guidance. Assessment, from this “caregiver as client” perspective, focuses on how they are managing their responsibilities and ways to protect their health and safety; caregiving demands place them at high risk for depression, injury and other adverse events. The policy goal is to prevent family caregivers from becoming patients themselves. It is the “right thing to do” and avoids greater public costs to care for the caregiver.

Second, family caregivers are viewed as unpaid providers who often need help to be competent, safe “workers” able to support their family

References


Family caregivers can be seen as both clients and providers; each view has public policy implications.

5 Susan Reinhard is now Director, Public Policy Institute, AARP.
members (i.e., the care recipients) and protect them from harm (e.g., falling between the bed and the wheelchair). From this “caregiver as provider” perspective, assessment focuses on determining needs for caregiver education and training and other support services (e.g., respite care, counseling). The policy goal is to keep family caregivers “on the job”. It is the “right thing to do” and avoids greater public costs to care for the care recipient in a nursing home setting.

Advancing caregiver assessment to help caregivers in their own right (i.e., “caregivers as client”) has a strong advocacy platform, and using the “caregiver as provider” perspective is compelling in the current policy environment. A strong case can be made that if the government is paying for an individual's care, and that individual's plan of care relies on support from the family caregiver, the government should require and fund a caregiver assessment. How else could the government know that there is emergency backup or a contingency plan if a family caregiver cannot provide the care that is assumed or stated in the plan of care?

Change Strategies. The National Consensus Development Conference for Caregiver Assessment identified specific strategies over the next several years to promote policy development. The overall policy objective is to include standardized caregiver assessment as a basic component of good practice in all publicly funded programs.

In the first few years strategic action aims at building support for family caregiver assessment among the public, policymakers, government officials, practitioners, insurers, employers and funders. Examples include involving professional associations, adding questions on caregiving to the U.S. Census and the Center for Disease Control's surveys, and having the Centers for Medicare & Medicaid Services (CMS) incorporate caregiver assessment and support in the protocols for Medicaid-funded home and community programs and Medicare's chronic care programs. Ideally, the National Family Caregiver Support Program, the Alzheimer’s Disease Demonstration Grants to States, and the Aging and Disability Resource Centers (ADRCs) all would incorporate caregiver assessment by trained assessors.

After achieving broad support for caregiver assessment, the next focus is changing professional education and training curricula to include caregiver assessment and helping prepare social workers, nurses, and other professionals to implement this practice across all settings. Information systems that include caregiver assessment would support that practice. Starting in large health care systems, such as the Department of Veterans Affairs, is logical. A uniform data set and evaluative research would help clarify caregivers’ needs and contributions, resources to meet those needs, and the impact of different assessment approaches.
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| **A. Build support for family caregivers among the public, policymakers, government officials, practitioners, insurers, employers & funders (awareness and data)**  
- Add a question on caregiving to the U.S. Census  
- Add questions on caregiving to the Centers for Disease Control’s Behavioral Risk Factor Surveillance System (BRFSS) and state surveys  
- Involve professional associations to promote the use of caregiver assessments | **A. Adopt a caregiver policy at CMS to acknowledge role and contributions of caregivers in the Medicare & Medicaid programs** |
| **B. Conduct demonstration projects to develop & test caregiver assessment practices & protocols as part of the Older American Act’s National Family Caregiver Support Program (NFCSP)** | **B. Develop professional education and training curricula that include caregiver assessment** |
| **C. Include caregiver assessment by trained assessors in the NFCSP, Alzheimer’s Disease Demonstration Grants to States (ADDGS), and the Aging and Disability Resource Centers (ADRC) programs** | **C. Advocate for changing record keeping & information systems to include caregiver-related data elements. Focus on:**  
- Large health systems  
- Mandated reporting systems  
- Smaller electronic record systems |
| **D. Recognize the role of family caregivers in Medicare’s Chronic Care demonstrations** | **D. Support development of a uniform data set & evaluative research to clarify:**  
- Caregiver needs & contributions  
- Resources to meet needs of caregivers  
- Impact of different assessment approaches |
| **E. Incorporate caregiver assessment & support needs in Medicaid home & community-based services** | **F. Develop caregiver assessment algorithms to assist decision making** |
| **G. Add family caregiver assessment as a 6th category under the NFCSP** | **H. Expand dialogue with consumers to discuss caregiver assessment in consumer-directed models of care** |
Facilitating Factors and Issues. There is good news: A few states already envision a system of long term services and supports where family caregivers are recognized explicitly.

For example, strategic planning for North Carolina’s CMS-funded Systems Transformation Initiative led to a statewide mission and vision with families at the center:

“The mission is to create a statewide, integrated, person and family-centered system for those who need long term services and supports so that they can live and actively participate in communities of their choice.”

The vision is portrayed in the following figure:

A high-level policy group at CMS is planning ways to support family caregivers, including pilots in caregiver assessment. The Administration on Aging’s “Choices for Independence” may become a strong policy lever for family caregiver assessment and support. With the ADRCs now part of the Lifespan Respite law, we see more potential for advancing this agenda. Major philanthropic organizations also are showing serious and sustained attention, partnering with each other to maximize their investments in this area.
As family caregiver assessment becomes an essential component of practice and policy, other issues can be addressed. For example, younger persons with disabilities, who sometimes fear that a focus on the family may detract from person-centered planning, need to be included in this discussion. Some state officials worry that adding another assessment instrument into their programs will make things more complicated and expensive to administer. They also express concern about the need to “address it if we assess it.” Of course, that is the point.

Moving Forward. Those who support policy development in this arena should get involved with the strategic planning groups that are convening right now in about half the states. Talk to your legislators and other state and federal officials about the central importance of assessing caregivers’ needs and helping families find the support that will keep them healthy and “on the job” if they choose. This change will not happen immediately but it is progressing. We need sustained advocacy to progress further and faster.
The Link Between the Informal and Formal Care Networks: Why We Should Care

Robyn Stone, DrPH
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American Association for Homes and Services for the Aging

Together, close to 4 million family members and an estimated 2.6 million direct care workers (DCWs)—nursing assistants, home health and home care aides, personal care workers—provide up to 90 percent of all long-term care services for frail elders in this country. Recognizing and strengthening the linkages between informal and formal care networks is important for several reasons. First, both are the “eyes and ears” of the care recipient; they are the first responders to address the functional and emotional needs of older persons and to recognize subtle changes in chronic conditions. Second, both groups require similar skill sets and knowledge to be successful caregivers, including training in the technical/clinical aspects of care.
delivery as well as more fundamental information about the aging process and chronic disability. Third, effective communication between the family and DCWs is essential to maximizing the quality of care and quality of life of the older person receiving services across all settings—nursing homes, assisted living facilities, other residential and community-based settings and private homes. Lastly, the hard work and contributions to care delivery of both DCWs and informal caregivers are frequently taken as “givens”—they are often invisible to the larger society. Family caregivers are unpaid and DCWs are poorly paid; most are female and are doing what society views as “woman’s work.”

The Future. The graying of America and, in particular, the disproportionate growth in the 85+ population, will increase the demand for informal and formal caregivers. As the home and community-based sector expands, the need for caregivers in non-institutional settings will grow. The expected greater proportion of nursing home residents with higher acuity levels will place additional pressures on caregivers in this setting. Moreover, the pool of family caregivers available to meet these needs will be smaller and the labor pool of women who have traditionally filled DCW positions is projected to shrink substantially. What will increase is cultural diversity—among the DCWs as well as the older adults needing services. Without a significant investment in cultural competence training and support, this trend could be a recipe for disaster.

What Does the Future Hold?

- Increased demand for services, particularly in non-institutional settings
- Higher acuity levels of care recipients
- Potentially smaller family caregiver pool
- Shrinking DCW labor pool
- Increased cultural diversity among caregivers & care recipients
- Greater divide between “haves” and “have nots”

A Linked Policy Agenda. Any long-term care financing reform that shifts more responsibility to either the public or private sector will affect families’ resources to purchase care and dollars that are available to pay DCWs. As states aggressively pursue Medicaid reforms to “rebalance” the care system away from institutions into home and community-based settings, the need to prepare a quality home care workforce grows. So do pressures on family caregivers to help their elderly relatives remain in the community. The expansion of consumer direction in publicly subsidized home and community-based services is allowing families more
choices in the use of resources. Their options include paying themselves or other relatives and friends to provide direct care or hiring DCWs in the private market. Consumer direction thus places more decision-making responsibilities on families about how limited resources will be used and may encourage the expansion of independent DCW providers without the same wages and benefits that employees of home care agencies receive.

**Opportunities for Joint Efforts.** Several strategies could link family caregivers and DCWs, improve the status of each group and enhance the quality of services provided to older adults needing long-term care. First, joint training programs could provide family members and DCWs the technical, clinical and communication skills required to be effective caregivers. Second, joint development by family caregivers and DCWs of cultural competence programs, focused on unique cultural values, views and traditions, could facilitate better communication and collaboration. Third, joint advocacy positions and activities could focus on policy issues such as how to finance long-term care, improving reimbursement for DCW wages and benefits, expanding family caregiver support programs and developing training requirements and educational programs that benefit both the DCWs and family caregivers.

**Areas for Informal/Formal Care Links**

- Joint training programs (clinical, technical, communication skills)
- Development of model cultural competence programs
- Joint advocacy
  - LTC reform
  - Reimbursement policy
  - Family caregiver support programs
  - DCW wages and benefits
  - Education/training requirements and support

**References**


Interface between Family Caregivers and Direct Care Workers

Gail Hunt
President & CEO
National Alliance for Caregiving

Although the family caregiver is the backbone of the long-term care system, the role of the direct care worker (DCW) grows more important as the population ages, as there is more chronic illness, and as family caregivers become increasingly scarce and burdened with balancing work and family. The supply of DCWs is also scarce. Recruitment for DCW jobs from the traditional American workforce, such as high school students, is difficult, and we are depending more upon an immigrant population.

Training Needs. Family caregivers and DCWs are increasingly seen as needing similar hands-on training—in skill areas such as personal care (e.g., how to give a bed bath), transfer techniques, nutrition, home safety and proper use of devices such as respirators, catheters and suctioning machines. A United Hospital Fund/Harvard School of Public Health survey of New York State family caregivers revealed that only 19 percent of family members had received any training. Most DCWs who work for a home health agency have only minimal state-required training—just a day or two. Privately hired workers may have no formal training at all. Beyond hands-on training, DCWs as well as family members could also use training in stress management, decision-making, communication and how to access community resources.

A few recent activities are focusing on joint training for family caregivers and DCWs. The International Longevity Center in New York’s “Caregiving Project for Older Americans” is testing a joint training program, offered through local community colleges, for family caregivers and in-home DCWs. It builds on a pilot project of the Schmieding Center in Arkansas. The Rosalyn Carter Institute in Americus, Georgia, also has a new initiative, the National Quality Care Network, that includes training. Its focus is the quality of long-term care, including evidence-based interventions that involve family caregivers as well as professionals and DCWs. This project’s first component is to examine existing caregiver training programs to see which training outcomes have the most impact on the quality of care.

Communication Issues and Diversity. Currently there appears to be a mismatch between the formal organizational structure of long-term care and the tasks expected of the family. For example, hospitals frequently discharge frail elderly patients to their equally frail and elderly
spouses, with just a list of medications and a treatment regimen. When care recipients are in the hospital or nursing home, family caregivers are seldom consulted and sometimes ignored. Family caregivers are sometimes afraid to express their opinions or intervene in care for fear of “retribution” against the care recipient. Cultural differences between the formal long-term care system and the caregiver can exacerbate the communication issues. One solution seems to be training programs for family caregivers, formal care providers (e.g., physicians, nurses, social workers) and DCWs in active/empathetic listening, to better understand roles and perceptions.

**Care Coordination.** Optimally, care coordination engages the family caregiver, the healthcare professional, the DCW and the care recipient to execute the care plan. Traditionally, care coordination difficulties occur because of the many professionals involved in providing care and the different funding silos. Research has generally focused on the role of the professional in care coordination: New efforts need to include the DCW’s role as well. In the case of electronic Personal Health Records, for example, the DCW may have important patient information that should be included.

Between family caregivers and DCWs several questions arise about responsibilities, oversight of care in the home, the appropriate relationship of the doctor, home care agency, therapist, and nurse to both the family caregiver and the DCW, the appropriate relationship between the family caregiver and the DCW in the home and, as technology increases to support in-home care caregivers, its role for both family caregivers and DCWs.

**Care Coordination Questions for Family Caregivers and Direct Care Workers**

- Who is responsible for what tasks in the home?
- Who oversees care and its coordination in the home?
- How should professionals relate to both the family caregiver and the DCW?
- How should the family caregiver and the DCW relate to each other in the home?
- How can technology aid family caregivers and DCWs in the home?

**Challenging Trends.** Several trends are blurring the line between the informal and formal care networks, impacting how family caregivers and DCWs interact. First, efforts to “rebalance” long-term care from institutional care to more home and community-based services means that...
more care for persons with chronic or disabling conditions falls to family members, whether or not they are prepared, willing and trained. Second, significant numbers of DCWs are also family caregivers. A survey conducted by Home Instead, a home care agency, found that 60 percent of their employees were also family caregivers. Third, under the consumer direction movement, more and more family caregivers are being paid to provide care. Today 15 states have Cash & Counseling programs, where disabled Medicaid beneficiaries receive cash vouchers that can be used to pay family members to provide their care. In several states, the Service Employees International Union (SEIU) requires family caregivers who are paid to provide care to become union members and pay dues. Lastly, corporations developing high-tech devices (e.g., handheld telehealth devices, websites and decision support systems) should assume that both family caregivers and DCWs will be users and design training for both.

A Workforce Perspective on Caregiving

Dorie Seavey, PhD
Director of Policy Research
Paraprofessional Healthcare Institute

Our Common Predicament and Challenge. The worlds of family and paid caregiving face a common predicament: Namely, a profound population-driven mismatch between the number of people needing care and those available to provide care. Consumer preferences and public policy also play important roles in fueling this gap.

The mismatch is structural and quite significant. On the family caregiver side, the population of adults over age 65 is growing at three times the rate of the population of family members available to care for them, primarily spouses and adult children aged 45 to 64 years. On the workforce side, the demand for paraprofessionals or direct care workers (DCWs) is expected to grow by 35 percent from 2004 to 2014. Over roughly the same time frame, the traditional labor pool from which these workers are drawn—women aged 25-54—will barely hold its own, increasing by under two percent.
Our common challenge is clear: How can we meet society’s need for more quality caregiving, both family and formal, both paid and unpaid, at a time when:

- The family caregiving “system” is increasingly stressed. Growing caregiving responsibilities are pressuring more women to retire early or move from full-time to part-time work. According to health experts, the adverse health impacts of overburdened caregivers now constitute an emergent public health issue.

- Across the country, poor quality direct-care jobs result in workforce instability and labor shortages. Our service delivery system largely relies on the labor of working-poor females (including many single parents and women of color). They cannot support their families with what they earn doing direct-care work and often lack health insurance. Their jobs usually come with minimal training, the work is often erratic and part-time, and career paths typically are unavailable.

The Caregiving Continuum. We usually think about and treat family and paid caregiving as two separate worlds. This “separate worlds” paradigm has led to largely independent policy agendas, refined at separate conferences and other forums, which potentially compete for the same attention and resources. In this paradigm, family care is seen as the core of all caregiving; paid caregiving appears to play a minor role, often only after family care has been depleted or exhausted.

Our actual practices, however, have outgrown this separate world paradigm. The family/paid caregiving continuum is in fact a richer, more complex array. The caregiving continuum recognizes emerging complexities such as the blurring of lines between formal and informal caregiving, and the fact that, for any one consumer, care arrangements are dynamic. Over time, one type of care arrangement may be substituted for or complemented with another.
for or complemented with another. It also allows for variation in actual caregiving arrangements depending on the care recipient’s socio-economic background, including age, and the nature of the individual’s disability or chronic disease.

In addition, the continuum encompasses the reality that, while the majority of consumers depend on unpaid family care, reliance on paid family care at home is the “arrangement of choice” for a growing number of Medicaid consumers, usually under consumer direction programs, such as Cash and Counseling. The continuum also includes the many private-pay consumers who rely on the so-called “grey market” of paid non-relatives who are not agency-directed, as well as the millions of Americans who receive supports and services from home care agencies, nursing facilities, adult day programs, group homes, and residential care and assisted living facilities.

**Collaboration to Create New Ways of Organizing and Supporting Caregiving.** From a policy and advocacy perspective, it no longer makes sense to treat family and formal caregiving as two separate worlds. Rather, family and paid caregivers, and their advocates, need to work towards an integrated agenda, supported by explicit partnerships and alliances. We

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<td>Family, Friends, Neighbors &amp; Volunteers</td>
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**Goals of an Integrated Agenda to Support Caregiving**

- Coordinate caregiving across settings
- Integrate medical and social needs
- Blend formal and family/informal caregiving as needed
- Offer interdisciplinary care that addresses needs of care recipients and caregivers
- Value and support paid and unpaid caregiving labor
need to advocate for and pursue new caregiving models that coordinate caregiving for long-term care consumers across settings; integrate medical and social needs; blend formal caregiving as needed with family and informal caregiving; offer comprehensive, interdisciplinary care-management frameworks that address the needs of care recipients as well as those of caregivers; and value and support caregiving labor, both unpaid and paid, so that all caregivers can be respected and economically self-sufficient in their working years and in retirement.

References


Family caregiving has many features we associate with chronic stress experiences. Duration of the event and of the response is chronic; the stressors inherent in the caregiving situation are persistent, uncontrollable and often unpredictable; and, in the case of illnesses such as Alzheimer’s disease, it requires high levels of vigilance on the part of the caregiver. Caregiving generates both physical and psychological strain with little opportunity for adaptation, and it has the capacity to generate secondary stress in multiple life domains such as finances, work and family relationships.

Because of the high levels of chronic stress inherent in caregiving, we have been interested in studying the health effects of caregiving. We
have been following several large populations to document changes in health as family members enter and leave the caregiving role. As caregivers move into, through and out of the caregiving experience as a result of death or placement, how does this impact their psychological appraisal of the situation and their health status? How might one intervene to address the negative effects of caregiving? Answers to these questions are summarized in the figure below.

**Becoming a Caregiver.** Longitudinal research assessing the effects of becoming a caregiver and moving from light duty to heavy duty caregiving shows that moving from light to heavy duty caregiving is associated with the largest negative health effects. Caregivers report increased depressive symptoms, decreases in self-reported health, neglect of important self-care behaviors, weight loss among older spousal caregivers and increased chronic illness due to having to provide assistance to their relative with activities of daily living (ADL). Strained spousal caregivers also show increased rates of mortality when compared to non-caregiving controls (Burton, Zdaniuk, Schulz et al., 2003; Burton, Newsom, Schulz et al., 1997; Schulz & Beach, 1999).

**Caregiver Exit Transitions.** What happens to the caregiver after the care recipient dies? Most caregivers show remarkable resilience to the death of their loved one. There is no evidence of increased depression or negative health effects after death. In contrast, after a loved one’s death non-caretakers show increases in depression, anti-depressant medication use and weight loss. Except for about 20 percent of caregivers who report high levels of depression, most caregivers report near normal levels of depressive symptoms about a year post-death. The relatively benign and sometimes positive effects of death may be
due to caregivers’ having had more opportunity to rehearse and prepare for the death, and it often marks the end of the patient’s and caregiver’s suffering (Schulz, Mendelsohn, Haley et al., 2003; Schulz, Beach, Lind et al., 2001).

The impact of placing a relative in a long-term care facility is not the same as with as death. Caregivers continue to be depressed and are more likely to increase their intake of anti-anxiety medication (Schulz, Belle, Czaja et al., 2004).

**Conclusion and New Opportunities for Research.** For many family members, caregiving evolves into a chronically stressful experience that contributes in multiple ways to both psychiatric and physical illness, and in some cases, leads to mortality. The many sources of stress include the functional disability of the care recipient, the work and frustrations of caregiving, the vigilant demands of caregiving, and secondary stressors such as financial problems and impaired family relationships.

One factor has received relatively little attention and assessing its role should deepen our understanding of the caregiving experience and open new opportunities for caregiver interventions. That factor is patient suffering. The model shown below places patient suffering into the context of the caregiving experience.

![Patient Suffering in the Caregiver Stress Health Model](image)

Suffering overlaps with but is distinct from the illness and its associated disability. It includes the overt physical signs of pain and discomfort, the patient’s distress about what is happening, and the patient’s ability to make sense spiritually or existentially of the situation. Addressing patient suffering through interventions provides new opportunities for research that should be beneficial to both patients and caregivers.
References


Caregiver Outcomes: The Public Health Perspective

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Caregiving is an increasingly important public health issue, and one that may be addressed in a variety of ways (Talley & Crews, 2007).
Population-level data on caregivers offer a different approach than the in-depth findings from research and interventions. One benefit is that broader inclusion criteria apply. For example, we include caregivers across the lifespan regardless of the impairment(s) of their care recipients or the type or amount of care provided. Further, these data are meaningful at a state level.

The BRFSS. The Behavioral Risk Factor Surveillance System (BRFSS) of The Centers for Disease Control and Prevention (CDC) (see www.cdc.gov/brfss) is the world’s largest telephone survey and a major source of health and risk factor data in the U.S. A state-based system, BRFSS telephone surveys generate information about health risk behaviors, clinical prevention practices, and health care access and use related to chronic diseases, injuries and death. In the past, BRFSS included two caregiving questions and several care-recipient questions. However, these questions were limited by the age group of care recipients, aged 60 and older, and the amount of detail about caregiving activities and outcomes.

With stakeholder input and a review of other caregiving surveys, we created a 10-item Caregiver Module plus a 20-minute in depth follow-back interview, using the framework from *Healthy People 2010* (Chapter 6) and the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF). As stated in *Healthy People 2010*, “whether caring for infants, children or adults with disabilities or for the increasing number of people who become activity-limited as they grow older, the caregiver is an important health component.”

### Public Health Framework for People with Disabilities

*Healthy People 2010 Chapter 6*

- **Goal:** Promote the health of people with disabilities, prevent secondary conditions, eliminate disparities between people with & without disabilities in the U.S. population

- **Objective 6-13:** Increase public health surveillance & health promotion programs for people with disabilities & caregivers

We pilot-tested our set of state-added questions and follow-back survey during the 2005 North Carolina BRFSS. Of 5,859 respondents screened
by telephone, we identified 895 caregivers (15.5%, 95% confidence interval [CI]: 14.2, 16.9). Caregivers tended to be older than non-caregivers (mean age 46.4 years compared to 45.6) and more likely to be female (59.5% versus 51.1%). Overall, caregivers reported better general health (general health reported fair or poor by 16.5% of caregivers and 19.1% of non-caregivers). However, caregivers had more days of poor physical health in the previous 30 days than non-caregivers (mean 4.3 days compared to 3.0) and were more likely to say they rarely or never received the emotional support needed (8.4% compared to 7.7%).

Caregivers provided an average of 20.1 hours per week of care and had been providing care for 42.5 months (mean). Nearly one in four (24.9%) caregivers lived with the person receiving care, while another two in four (47.3%) lived within 20 minutes. Caregivers reported stress (29.9%) and not having enough time for themselves or family members (27.9%) as the greatest difficulties they faced in caregiving. Nearly 4 percent of caregivers reported an injury related to caregiving in the past year.

A preliminary look at the unweighted follow-back results showed caregivers’ situations vary tremendously. Only one in three of the North Carolina caregivers considered themselves to be the primary caregiver (another 18% said they split responsibilities evenly with someone else). Over 10 percent of respondents said no one else would be there to provide care if s/he became sick or unable to give care and more than two in five (42.4%) caregivers did not feel they had a choice in taking on the caregiving role. Although almost one-fourth of the caregiver group (23.0%) said caregiving was not at all stressful, more than one in six (18.3%) found it very emotionally stressful. Caregivers reported dealing with stress through prayer (84.0%), talking with friends or relatives (63.7%), reading about caregiving (48.7%), and exercising (48.3%).

We adjusted for age, gender, race and income to compare caregivers with non-caregivers on a range of health behaviors and conditions. Caregivers were more likely to have exercised in the past month (odds ration [OR] =1.55, p<0.05), ever had their cholesterol checked (OR=1.21, p>0.05), had a flu shot in the past year (OR=1.62, p<0.05), or taken a class to manage diabetes (OR=1.28, p>0.05). However, they were more likely than non-caregivers to report joint pain in the past month (OR=1.17, p>0.05), or say they could not see a doctor because of cost (OR=1.62, p<0.05).

Implications and Future Directions. Caregivers may be at risk for negative health outcomes, including stress, and report other factors, such as role captivity, that may contribute to increased stress (Pinquart & Sorensen, 2003; Schuz et al., 1997; Schulz, Visintainer & Williamson, 1990). The BRFSS pilot test in North Carolina seems to confirm this research. While revealing that caregivers may be more likely to
participate in health promotion activities, they also appear to be more at risk for poor mental health outcomes than non-caregivers.

The Caregiver Module is scheduled to be cognitively tested by CDC this summer for inclusion as an official BRFSS Module in 2009. In the meantime, states may choose to use these questions to begin collecting relevant data on caregiving. Four states (Hawaii, Kansas, Rhode Island, Washington) are using the Caregiver Module in 2007 as part of their 2007 BRFSS questions. A state wanting to use the Caregiver Module should contact the BRFSS Coordinator (listed at http://www.cdc.gov/brfss/stateinfo.htm) as soon as possible; the survey fills quickly each year. Each state’s BRFSS Coordinator can provide information on cost and specific procedures, including access to data. Support from a variety of departments or organizations related to caregiving, aging, chronic disease, disability, etc. will improve the likelihood that a state will opt to include caregiver surveillance on its BRFSS.

References


It only takes a few statistics to give a sense of the size and scope of the issue of providing family caregiving in rural and frontier communities. The U.S. is very large. As a comparatively young country, it still reflects much of the early settlement patterns. The Kellogg Foundation describes Rural America as 80 percent of the land area of the U.S. and about 55 million people (about 18% of the U.S. population). Continuing along the settlement continuum, Frontier includes 56 percent of the land area and about three to four percent of the population, or about 10 million people. These numbers provide a snapshot of a very large area with numerous major cities along the coasts and a handful scattered across the center of the country; much of the rest of the population lives in small towns and widely scattered isolated farms, ranches and villages.

The rural and frontier populations in the U.S. are older and poorer than the nation as a whole. An ongoing shortage of health professionals of all
types impacts significantly on caregiving in rural and frontier populations. Accessing even essential services is a challenge and barriers to family care are huge.

**Demographic Trends.** It is “a given” that distance and a small population base impact many programs and services in non-urban communities. Having a population older than the national average affects family caregiving in rural and frontier communities especially. There are exceptions, of course. The populations of Native Americans and communities with high immigration rates are generally younger. But in many states, the rural and frontier populations have higher rates of elderly and these residents also experience higher rates of disability.

Elderly residents in small communities want the same right to “age in place” and in their own home as those living in larger communities. In a small community with a high proportion of elderly and disabled adults, who is there to provide family caregiving? Too frequently, the younger generation has left and has no plans to return. Bringing these two disparate realities together does not entail simple solutions. Success depends upon a major national policy shift. Healthy rural economies with job opportunities must be created so that young people will want to return to their communities after completing their education and/or job training. We must have jobs and activities and respite for adult children returning home to care for elderly parents.

Over the past 10 years the National Center for Frontier Communities has studied the challenges facing small communities. The Center has found that many existing barriers are accidental, stemming from the use of urban models and programs by policymakers rather than from any conscious intent to create programs that do not work in small communities.

**Rights-Based Policy.** A major paradigm shift in thinking about small communities is required. “Place” needs to be understood as a civil right. As we work together for an equal right to services and resources, discrimination based on where you live must end.

**Strategies for the Future.** Two strategies could increase access to quality services in rural and frontier communities:

1. Unite to create a national consensus about universal access to essential services. Where you live and who you are should not affect your ability to access essential services, especially in times of greatest need.

2. Work for policies that value families, whatever their configuration, which is very different from the empty rhetoric of family values.
Caregiving and the Latino Community

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When thinking about caregiving in the context of the Latino community, one must consider the demographics of this population in the U.S. Latinos are the biggest minority group in the country and tend to be younger and poorer than other groups in the U.S. Despite their relative youth, Latinos experience high rates of chronic health conditions, due in part to a lack of access to health care and in part to the types of rigorous manual labor that many Latinos do.

Latinos also are a major part of the cheap labor force within the health care industry. In particular, Latinas and other women of color make up the vast majority of the direct care workforce. They act in many ways as the “caregivers of last resort” for older and disabled adults who may not have family members to care for them.

When reaching out to the Latino community of caregivers, providing culturally competent services is crucial, as is considering literacy levels. Different subgroups of Latinos and immigrants have different levels of literacy—in Spanish as well as in English. Simply translating materials from English to Spanish does not provide adequate community education if these materials are not designed for the literacy and cultural competence levels of the target populations.

Given population trends, policymakers and professionals in the field of aging must face several key questions:

- How are we going to deal with a younger, diverse caregiving workforce population and an older, predominantly white population in need of care services?
- How do we develop conflict resolution training?
- How are we going to educate and train a direct care workforce comprised mainly of women of color and immigrants?
- Are we going to commit to paying direct care workers fair wages?
- Will aging service providers be willing to allocate dollars to create “caregiving” programs, information, etc., that address the unique needs of mono-lingual and culturally diverse older adults?
Finally, the issues and concerns of minority older persons must be placed in the “WHOLE” context of the need for supportive services and caregiving, not just as a side issue. The demographic/cultural changes taking place across the country must create an impetus for Aging Network policymakers to reflect these changes in the policy deliberations and in the design and development of both old and new caregiving service models.

Strategies for Meeting the Needs of LGBT Caregivers

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Any discussion about LGBT caregivers must begin with a definition of the group to whom we are referring. Otherwise, we run the risk that inaccurate assumptions may be made as to who LGBT caregivers are. All too often, “LGBT” is assumed to equal “gay,” when in fact, the LGBT community is rich with diversity and includes individuals who self-identify as heterosexual or “straight.” For the purposes of this discussion, “LGBT caregivers” refers to a group of caregivers that includes: Lesbian women, gay men, bisexual women, bisexual men, transgender heterosexual women, transgender lesbian women, transgender bisexual women, transgender heterosexual men, transgender gay men, and transgender bisexual men.

Major Issues and Themes. As with all caregivers, LGBT caregivers may be caring for a spouse or partner, a parent, a child, a sibling, a neighbor, or a friend, among others. They also may be caring for more than one care recipient. LGBT caregivers are similar to other caregivers in that they juggle caregiving, work and family responsibilities, but homophobia and heterosexism may add to the already-heavy load they are carrying.

In America, LGBT individuals (including LGBT caregivers) have unequal access to services and benefits due to discriminatory policies and practices from the federal level down to state and local levels (National Gay and Lesbian Task Force, 2000). It is not unreasonable to surmise that this may have an impact on the ways in which LGBT caregivers approach, experience and evaluate their interactions with the health care and social services systems in the U.S. Yet, it is hard to know the exact
challenges and issues that LGBT caregivers face. Some data on lesbian, gay and bisexual caregivers exist, but more research is needed, particularly with regard to the challenges faced by transgender caregivers.

LGBT caregivers may have spent a lifetime dealing with fear, hatred, scorn, discrimination, violence and/or the threat of violence. Given the messages that LGBT caregivers have heard over a lifetime about how society values them as human beings, it is not surprising that they may be reluctant to tell service providers that they are lesbian, gay, bisexual, and/or transgender, or even to ask for help from social service agencies in the first place. As such, service providers cannot put the burden on LGBT caregivers to “come out.” The onus is on us as professionals to provide care and services in a manner that conveys our respect for each and every caregiver with whom we interact.

**Recommendations.** As a step towards ensuring the provision of optimal care and services to LGBT caregivers, service providers may want to consider carrying out a cyclical process of reflection, advocacy, education and bridge-building at the individual and organizational levels. Six steps can help you get started:

**Step 1: Look within Yourself**
- Recognize your own assumptions and biases.
- Do you assume a caregiver is heterosexual (“straight”) unless they tell you otherwise?
- Do you have a preconceived notion of what a “gay caregiver,” “lesbian caregiver,” “transgender caregiver” or “bisexual caregiver” looks like?
- How comfortable do you feel with LGBT clients?

**Step 2: Look within Your Agency**
- Whom does your agency serve?
- Has the agency served LGBT caregivers in the past?
- What about now—are there any LGBT caregivers receiving services? What about LGBT people in general?
- What does your agency’s nondiscrimination statement say? Are “sexual orientation,” “gender identity” and “gender expression” included?
- Whom does your agency employ? Do you have “out” LGBT staff members?
Step 3: Look within Your Community

- Think about the community as a whole, then
- Ask four key questions at your agency:
  » “Who is missing?” (in terms of the caregivers you serve)
  » “Why are they missing?”
  » “Where are they?”
  » “What can I do to build a bridge to them?”

Step 4: Advocate for Change at the Institutional Level

- Advocacy on behalf of LGBT caregivers goes beyond one-on-one practice.
- Service providers can serve as catalysts for institutional change as well—to increase access and quality of services and ensure LGBT caregivers are having their needs met.

Step 5: Educate

- Educate yourself, then work to educate your agency.
- Service providers need to understand, value and respect the perspective of LGBT caregivers.
- Supervision provides an excellent opportunity for service providers to explore their own fears, biases and anxieties about working with LGBT clients.
- Try not to scold colleagues or students for verbalizing their fears and/or biases to you. Remember, shutting them down does not make the bias go away.

Step 6: Build Bridges

- Build bridges to LGBT caregivers and care recipients, LGBT staff and the LGBT community as a whole.
- Let the community know that your agency is committed to meeting the needs of ALL caregivers, including LGBT caregivers.
References


Concurrent Workshops: Promising Practices and Research Trends

Leading Edge Caregiver Interventions

Moderator: Vicki Schmall, PhD
Consultant in Aging Services

New Models for Caring for the Caregiver: What, How, When and Where Should We Intervene?

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The past 20 years of caregiver intervention research has yielded a vast array of promising approaches for supporting family caregiving efforts. Continued research to identify innovative, cost-efficient interventions for diverse families, facing different chronic conditions, is needed but equally important is the translation of existing proven programs into everyday practices.

Analytical Model. A social ecological model, based on a public health framework, has value for organizing and understanding evidence-based approaches to helping families. Using this model, four levels of influence on the well-being of families are identified. Specific interventions can be introduced at each level with the goal of supporting caregivers. Also, the
model suggests that interventions can be integrated across these four levels of influence to provide a comprehensive and systematic service approach to supporting families.

Specifically, in our ecological model, we view the health and well-being of family caregivers as embedded in multiple levels of influence, each having possibilities for modification through intervention. We identify four levels of influence on families: (1) the individual or the impaired older adult for whom care is provided; (2) the caregiver and/or family member(s); (3) the organizational environment (e.g., dyadic relationship between caregiver and impaired adult, or organizational care context for impaired adult); and (4) society-at-large as reflected in national health policies and legislative efforts.

For each level of influence identified in the model, we discuss here specific tested interventions designed for caregivers of individuals with dementia, a group at high risk of depression, poor physical health and mortality. Although interventions that target each level of influence do differ, common features can be implemented across the types. These commonalities include customizing strategies to fit specific person-environmental constellations or caregiver needs; focusing on specific, contextual needs of caregivers or familial units, using a client-driven rather than prescriptive framework; emphasizing change to behavioral, psycho-social and environmental factors through non-pharmacological
solutions; and reducing modifiable factors that place family caregivers at risk for poor health and for using nursing home placement.

**Individual Level.** An illustration shows how an intervention targeted at the individual level can also relieve burdens on the family caregiver. The Tailored Activity Program (TAP), funded by the National Institute of Mental Health (NIMH), targets individuals with dementia, aiming to reduce excess disability. TAP is an eight-session in-home program. In TAP, an occupational therapist develops activities tailored to the preserved capabilities of persons with dementia and instructs caregivers to implement and use activities effectively in daily care. Findings suggest that the TAP program reduces the occurrence of neuro-psychiatric behaviors in persons with dementia, the very behaviors which often trigger nursing home placement and which increase the amount of hands-on time required by families. The program also enhances caregiver sense of overall mastery and self-confidence in using activities.

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**TAP Intervention**

- 8 home sessions by occupational therapist
- **Systematic assessment:**
  » Person’s capabilities, previous roles, habits and interests
  » Physical environment
  » Caregiver communication and management strategies
- Develop customized activities that match capacity, previous/current interests, roles
- Train family caregiver in setting up and using tailored activities as part of daily care

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**Caregiver Level.** At the caregiver level, numerous promising multi-component interventions have been tested to address the needs of families (see Sörensen et al., 2002 for review). Examples of proven programs for dementia caregivers involve in-home skills training, psycho-social support groups, telephone support groups and care management services (Gitlin et al., 2003; Gitlin, et al., 2006; Winter & Gitlin, 2006; Mittelman et a., 2006). Caregiver level interventions have been recently designed and tested through a national multi-site effort known as Resources for Enhancing Alzheimer’s Caregiver Health, or REACH, funded by the National Institute on Aging/National Institute of Mental Health.

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6 “Excess disability” is disability that is disproportionate to the underlying condition or impairment.
of Nursing Research (NIA/NINR). An example is the REACH I Philadelphia site, which tested a six-visit home intervention.

Through their visits, an occupational therapist taught environmental modification, problem solving, communication and task simplification skills, and a physical therapist taught safe fall recovery techniques and proper body mechanics when providing physical care. Caregivers reported reduced upset with dementia-related behaviors and improved affect following this skill-building intervention.

**NIA/NINR REACH Multi-Site Studies**

- **REACH I**: 6-sites each testing an innovative intervention targeting family caregiver  
  » Home, individualized  
  » Group support  
  » Primary care  
  » Education
- **REACH II**: Multi-component home-based intervention tested at 5 sites involving Hispanic, White and African-American family caregivers

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**Organizational Level.** Organizational-level interventions target the family unit (impaired person and the family caregiver/s) or provide supportive services to caregivers as an integrated part of serving impaired older adults. An example of this integrated, familial unit approach is the Adult Day Service Plus program (ADS Plus). This program targeted families of impaired adults enrolled in adult day services. The study of ADS Plus showed that providing systematic education, problem solving and ongoing support to family caregivers reduced caregiver depression, improved confidence managing troublesome behaviors and enhanced overall well-being. Participants also used more days of adult day services and had fewer nursing home placements.

**The Societal Level.** At the societal level, policy resolutions can change the resource allocation and practice landscape. For example, the
National Family Caregiver Support Program (NFCSP), established with the enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501), has provided a mechanism for offering caregivers information, counseling, respite and other forms of assistance. While the program has not been systematically evaluated—and could benefit from the integration of evidence-based approaches—it exemplifies how interventions at the policy level can impact the landscape of supportive services for caregivers. Another example of a policy-level intervention is the work of the Family Caregiver Alliance’s National Center on Caregiving to advance the integration of systematic caregiver assessment into service provision (Family Caregiver Alliance, 2006).

**Conclusion and Next Steps.** Conceptualizing interventions from an ecological perspective positions caregiver well-being as a major public health concern, and it focuses understanding on what, when, where and how to intervene. Determining which intervention to implement may depend upon the level that is feasible to target (e.g., individual, familial, organization, or national policy), the preferred outcomes (e.g., caregiver depression, objective burden, or service delivery), or the specific familial needs or risk areas that need to be addressed. Certain potential benefits, such as reductions in depressive symptoms or objective burden, appear to be specific to the level which is targeted for intervention. For example, targeting the impaired person in Project TAP enhanced objective burden but did not reduce caregiver depressive symptoms whereas targeting the family caregiver directly through care management does appear to affect emotional well-being.

Some well-tested, promising programs are ready for translation into everyday practices but they will need further evaluation in the applied setting. Many of these proven interventions offer clinically meaningful approaches to managing complex consequences of caring for impaired adults. Nevertheless, the effort to translate interventions from the research environment into practice arenas does require resources to distill research-oriented protocols into clinical applications and evaluate their performance in an applied context. This translational effort should be a priority for funding agencies in order to close the research-practice gap that continues to haunt the field. There also is a pressing need for more systematic caregiver-intervention research continue to identify innovative approaches to support diverse caregiver populations and to assist those caring for individuals with a wide range of clinical conditions including cancer, stroke and spinal cord injury. Finally, research also is needed which considers why interventions work better for some caregivers and not others.
References


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The Lasting Benefits of Counseling and Support for Alzheimer’s Caregivers

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The past three decades have seen increasing interest in the development of interventions to help family caregivers of people with chronic illnesses. The majority of caregiver intervention studies have focused on family members of older adults with dementia. There are several reasons. An estimated five million people in the United States now suffer from dementia, and their families suffer with them. Moreover, caring for a relative with Alzheimer’s disease or related dementias is more difficult than other types of family caregiving. These caregivers must live with the knowledge that their relatives will inevitably continue to decline. They must cope with the troublesome behavior that is a hallmark of Alzheimer’s disease and their ill relatives’ diminishing ability to provide them with emotional support and to interact verbally. While the ill family member no longer can provide the same level of emotional support as before, other relatives and friends may be unaware of the caregiver’s need for support.

Model and Study Design. In the mid-1980s, we began a study at New York University (NYU) to evaluate the effectiveness of counseling and support for caregivers whose spouses had Alzheimer’s disease. Our clinical experience suggested that a multi-component individualized intervention would improve caregivers’ well-being and help them keep their husbands and wives home with them longer. The Stress Process Model, first described in 1990, suggests that an intervention that increased the quality of support for the caregiver and created more realistic appraisals of the behavior of the person with dementia could improve outcomes for both the caregiver and the person with dementia.

To test the efficacy of the intervention, we designed and conducted a randomized controlled trial, which has received NIH funding support for the past 20 years (1987 to 2007). The study’s design included a comprehensive baseline interview, random assignment to a treatment or control group, and regular comprehensive follow-up interviews. All participating caregivers received the services routinely available at the NYU Aging and Dementia Research Center.

Over a 9.5 year period, 406 spouse-caregivers enrolled in the study. They could continue to participate whether their spouse was at home or in a nursing home, and for two years after the person with dementia
died. The intervention (see figure below) included scheduled individual and family counseling sessions within four months of enrollment, and, for the entire course of the illness, ongoing participation in a support group that met weekly, and *ad hoc* counseling—telephone consultation on request of the spouse-caregiver or any other participating family member. A manual describing the intervention in detail was published in 2003 (Mittelman, Epstein & Pierzchala, 2003).

**NYU Spouse Caregiver Intervention Study: Treatment Schedule**

- **Within a fixed period of time**
  - An individual counseling session
  - 4 family counseling sessions
  - A second individual counseling session

- **Over the entire course of the disease**
  - Participation in a support group
  - Telephone consultation for caregiver or family member as needed.

Results. Numerous publications attest to the efficacy of the intervention. Its benefits include reduced symptoms of depression, reduced severity of reaction to problem behaviors, improved physical health of the caregiver and significantly postponed nursing home placement of the person with dementia. The central mechanism for achieving these effects was improved social support, specifically the number of friends and relatives the caregivers considered to be “close,” satisfaction with emotional support and with assistance from friends and relatives.

Replication. In the late 1990s, we began “The 3 Country Study,” a collaborative replication of the NYU study conducted by the author at the NYU School of Medicine, Henry Brodaty at Prince of Wales Hospital (Randwick, Australia), and Alistair Burns at Withington Hospital (Manchester, England). This first multinational randomized controlled trial of a psychosocial intervention for dementia caregivers was designed to answer two questions: (1) Does counseling and support for the family caregiver have benefits over and above the effects of drug treatment for Alzheimer’s disease? and (2) Is the effect of psychosocial support the same in all three countries (U.S., England and Australia)? The study involved 158 caregiver/patient pairs (at least 50 per country). All the people with dementia received a drug treatment (donepezil) and half the spouse-caregivers received the NYU counseling and support intervention in addition.

The results of The 3 Country Study replicated a major finding of the original NYU study, showing that a multi-component individualized intervention can have a significant impact on caregiver depression. This suggests that a combined psychosocial and pharmacologic intervention can be of substantial value to caregivers and people with dementia. Interestingly, we observed a significant difference in rates of nursing home placement across the countries. Australia, where the government pays for a higher proportion of the cost of nursing homes, had higher placement rates than the U.S., showing that medical and social care policies affect outcomes of psychosocial interventions.

Conclusion and Next Steps. The NYU studies and other well-designed caregiver intervention studies, such as REACH I and II, provide consistent findings:

(1) Psychosocial interventions for caregivers generally are effective in producing clinically and socially meaningful improvements in psychological well-being.

(2) Multi-component interventions are most effective.

(3) Interventions tailored to the needs of each individual are better than group interventions.
Interventions for caregivers of chronic diseases such as Alzheimer’s disease should be available for long periods of time. The results of these make it obvious that comprehensive care for people with dementia should include more than prescriptions for medication, and that widespread availability of counseling and support can have a major impact on the well-being of family caregivers and on their relatives with Alzheimer’s disease.

These interventions have proven efficacy in university research settings. The next step is to evaluate their effectiveness in community settings, with more diverse types of caregivers. Undoubtedly, modifications will have to be made to accommodate to the needs for additional medical, social and financial services, especially among caregivers who have until now been underserved, either because of ethnic or socioeconomic backgrounds.

References


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**Early-Stage Research and Practice for Persons with Cognitive Impairment and Their Family Caregivers**

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Benjamin Rose Institute

“Everything is so new. I’m just getting used to his different moods. I can’t keep up with them sometimes. Thank God I’m here to do it. I worry what would happen to him if I weren’t here.”

—Wife who cares for her husband with Alzheimer’s Disease

“I liked everything about this. It was the first opportunity I had to talk with a counselor about my problem.”

—Husband with dementia who is cared for by his wife

Intervention research for family caregivers of persons with cognitive impairment (PWCIs) typically focuses on preparing caregivers to cope with later stage problems such as behavior problems, assistance with activities of daily living (ADL), family conflict, depression and burden (Hepburn, Tornatore, Center, & Ostwald, 2001; Mittelman et al., 1995). These interventions often exclude the PWCIs based on two assumptions: (1) Family caregivers are more at risk for burden and distress, compared to PWCIs, and need more support and attention; and (2) PWCIs are limited in their ability to participate actively in the intervention process. However, research with persons in the early stages of cognitive impairment demonstrates that they are often as fully aware as their caregivers about
the meaning of their diagnosis and often have sufficient cognitive abilities to communicate choices and preferences (Whitlatch, Feinberg, & Tucke, 2005a; 2005b). An intervention that includes both members of the care dyad may be an optimal approach in early-stage dementia.

**Early Diagnosis Dyadic Intervention.** The Early Diagnosis Dyadic Intervention program (EDDI; Whitlatch et al., 2006) focuses on the dyad of care, involving the PWCI and caregiver as active participants and decision makers. The rationale for EDDI comes from the emerging interest in decision making and care preferences in chronic illness (High, 1988; Menne & Whitlatch, in press; Smerglia & Deimling, 1997; Walker & Allen, 1991; Wetle, Levkoff, Cwikel & Rosen, 1988). We have learned from this research that PWCI’s are willing to take responsibility for treatment decisions; that families benefit most when the PWCI’s and caregivers’ treatment goals and desires are mutually supported; and that caregivers who can discuss goals and preferences with their relative gain a better understanding of their relative and, as a result, feel better prepared and less burdened to make care decisions (Jacob, 1998).

The nine-session EDDI program has four main goals: (1) to help care partners develop positive communication patterns; (2) to increase the care partners’ knowledge and understanding of available services, care values, and preferences for care; (3) to increase the PWCI’s active participation in his/her care plan; and (4) to improve care partners’ well being and sense of self-efficacy in managing disease related issues. Care partners meet together and individually and separately with the EDDI counselor. The table below shows the topics covered within the EDDI sessions. These topic areas and the tools used in EDDI could be easily adapted for use with care dyads facing chronic conditions other than cognitive impairment.

### Early Diagnosis Dyadic Intervention (EDDI) Session Descriptions

<table>
<thead>
<tr>
<th>EDDI Session</th>
<th>Topic</th>
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<tbody>
<tr>
<td>Session 1: Information</td>
<td>Education about memory loss</td>
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<tr>
<td>Sessions 2-3: Care Values</td>
<td>Explore individual care values</td>
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<tr>
<td>Sessions 4-6: Care Preferences</td>
<td>Discuss preferences of care partner</td>
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<tr>
<td>Sessions 7-8: Challenges</td>
<td>Examine sources of formal and informal help</td>
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<td></td>
<td>Identify barriers and solutions to getting help</td>
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<tr>
<td>Session 9: Final Review</td>
<td>Review discussions and identify unresolved issues</td>
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**Results.** Evaluation of the EDDI program indicates that program satisfaction was higher and well-being generally improved for both members of the EDDI dyads, as compared to the control group who received treatment-as-usual (Whitlatch et al., 2006). In addition, caregivers...
were comfortable discussing sensitive topics, the dyads were able to work together on plans and PWCI s completed most or all of the intervention.

**Conclusion.** The EDDI results affirm the importance of consumer direction and empowerment for both care partners, including continued engagement in decision making for PWCI s that takes into account the context of the care relationship and the caregiver’s needs and preferences.

Public policies that support assessing and intervening with both care partners have the potential to enhance the efficacy of early-stage interventions. While there is much to be learned about dyadic interventions, the EDDI program provides one example of the importance of balancing the needs and priorities of both care partners.

**References**


“Integration of Caregivers in the Health Care System” describes an ideal partnership with health care providers. “Integration,” according to the dictionary, means “to form, coordinate, blend into a functional or unified whole.” Using this definition, most family caregivers are not integrated into the health care system or systems providing services to their family member. On the contrary, they are often actively “dis-integrated.” Their circumstances and other responsibilities are often ignored in care planning; their requests for information dismissed; their needs for training and support unmet; and major decisions reached without their involvement. This paper summarizes the reasons for their exclusion, outlines the importance of including family caregivers in transitional care plans, suggests some hopeful signs of progress and describes the United Hospital Fund’s efforts in this direction.
Causes of “Dis-Integration.” There are many reasons. First, the sole focus in insurance and medical practice traditionally has been on the patient/beneficiary, not on the family providing care. Providers say that they do not have time to talk to or train family caregivers, possibly because they are not paid to do so. Poor communication skills—on the part of both providers and family caregivers—break down trust. The privacy rules under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) have been misinterpreted and misapplied in many offices and institutions, leaving families without crucial information. Finally, the culture of medicine and health care generally sees families as “trouble”—intrusive and time-consuming—all the more reason to avoid dealing with them.

Why Dis-Integration Occurs

- Sole focus in insurance and professional practice on patient or beneficiary
- Lack of time for talking to or training family caregivers
- Lack of reimbursement for same
- Poor communication skills (providers and family)
- Misapplied HIPAA privacy rules
- Professional culture that sees families as “trouble”

Importance of Integration in Transitions. Health care today involves frequent moves from one setting to another—hospital to short-term nursing home stay, hospital to home, or even from one part of a hospital such as an ICU to another such as a rehab unit. Consider Mrs. Jones, who suffers a stroke. During the course of her treatment she is a patient in the Emergency Department and the ICU, has surgery, is a patient on a standard hospital floor, goes to a nursing home for a short-term stay, returns to the hospital for treatment of an infection, goes back to the nursing home and is discharged to home with short-term home care, outpatient rehab services and family care for her ongoing needs. Mrs. Jones is lucky. Some patients in her situation die after a cascade of problems.

Care transitions or “hand-offs” are fraught with the possibility of miscommunication between the sending and receiving staff and may lead to errors, particularly in medications. Transitions are also traumatic for patients and families, as they encounter new staff, new rules and a new culture. Besides being a familiar and reassuring presence for the patient, the family caregiver may be the only person who knows the patient intimately, can interpret verbal or nonverbal cues and has followed the
course of the illness from the beginning. Yet the caregiver’s expertise and important information are often ignored.

In the United Hospital Fund’s review of over 150 studies of transition care protocols, only a few mentioned family caregivers specifically. If family caregivers were mentioned, it was as “patient/family,” rather than a recognition of their special role and responsibilities. Many patients undergoing a series of transitions are sick, frail or have cognitive deficits; they do not fit the model of the fully self-directing “consumer,” able to understand, appreciate and follow complex medication regimens and make decisions without guidance and advice.

**Steps Toward Solutions.** Greater attention is being devoted to family caregivers in specific settings. For example, the American College of Critical Care Medicine Task Force guidelines (2007) on support of the family in the patient-centered ICU provide a model for all types of care. Among the recommendations are open and flexible visiting hours, presence of family on medical rounds, support for family stress and shared decision-making. Hospice and palliative care already recognize the family as the unit of care, and many of the best practices in end-of-life care (including reimbursement for family consultations) could be extended to other settings. JCAHO standards are beginning to recognize that family members are key participants in preventing medical error. The Agency for Healthcare Research and Quality (AHRQ) has included the consensus principles and practice guidelines for caregiver assessment from Family Caregiver Alliance’s National Consensus Development Conference (2006) in its National Guideline Clearinghouse. Some hospitals and health care systems have begun to do more to integrate family caregivers into their operations. Still, much more needs to be done.

**United Hospital Fund’s Campaign for Family Caregivers.** The United Hospital Fund’s Families and Health Care Project is developing a campaign to increase awareness, commitment and action among health care providers in hospitals, nursing homes and certified home health agencies. In three home care agencies, four nursing homes, and four hospitals, six survey instruments focused on transitions are being pilot tested (one for providers and one for family caregivers, in each setting). At the same time, we are developing tools to aid providers in action plans and to help family caregivers navigate an increasingly complex health care system.

The campaign will be launched late in 2007. Surveys and tools will be widely disseminated through a website and other means. The goal is to make the integration of caregivers in the health care system standard, not exceptional.
Chronic care in the U.S. is fragmented, discontinuous, difficult to access, inefficient, unsafe and expensive.

References


Integration of Caregivers in the Health System: The Guided Care Intervention

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Chronic care in the U.S. is fragmented, discontinuous, difficult to access, inefficient, unsafe and expensive. As a result, there is a growing consensus regarding the need for health care delivery systems that more effectively support patients’ chronic care. Several innovations that have individually proven to be successful include disease management, case management, transitional care, self-management, lifestyle modification, caregiver education and support, and geriatric evaluation and management. However, each of these innovations addresses only a subset of patients’ needs. There is increasing interest in more comprehensive, multifaceted interventions that simultaneously address physician practice, patient self management, and support for patients’ families. “Guided Care” is one such intervention.

The Model. “Guided Care” is a model of delivering chronic care for multimorbid older adults that explicitly recognizes and includes patients’ family caregivers. In Guided Care, a registered nurse who has completed a supplemental educational curriculum and joined a primary care practice works closely with several primary care physicians (PCPs). Together they address the chronic care needs of 50 to 60 patients who have multiple diagnoses and are at high risk for heavy use of health services during the coming year. Using a web-accessible electronic health record (EHR), the Guided Care nurse collaborates with the patient’s PCP to facilitate
eight clinical processes: (1) Assessing the patient and primary caregiver at home, (2) creating an evidence-based care plan, (3) promoting patient self-management, (4) proactively monitoring the patient’s conditions, (5) coaching the patient to practice healthy behaviors, (6) coordinating the patient’s transitions between sites and providers of care, (7) educating and supporting the caregiver and (8) facilitating access to community resources. A more detailed description of Guided Care has been published (Boyd, et al. 2007; in press).

**Trial.** A cluster-randomized trial of Guided Care is now underway in the Baltimore-Washington area. After completing a baseline interview with a professional survey research firm, patients and their primary caregivers were randomized by PCP to either Guided Care or usual care. A variety of health-related outcomes are being assessed for patients and their primary caregivers at 6 and 18 months follow-up. To establish the evidence needed to disseminate Guided Care, information about its financial viability and attractiveness to health care providers and insurers is also being collected.
Caregiver Definition. Because Guided Care is a lifetime model of care (patients are not discharged), the term “caregiver” is defined broadly as a relative or unpaid friend assisting the patient with health-related tasks. This definition reflects the belief that establishing productive working relationships with patients’ informal supports will mutually benefit both caregivers and patient care, and better prepare all involved parties when patients experience setbacks in their health. Because some individuals may not identify with the term “caregiver” and may even be offended by its use, in Guided Care the term “families and friends” is used whenever possible.

The “Guided Care Program for Families and Friends” includes the following components: (1) An initial in-person meeting between the nurse and the person the patient identifies as helping the most with health-related tasks, (2) education and referral to community resources, (3) ongoing “coaching” related to patients’ health-related needs, (4) a six-session Guided Care Nurse-facilitated Workshop, followed by (5) monthly Guided Care Nurse-facilitated Support Group meetings. Guided Care Nurses conduct all components of the Guided Care Program for Families and Friends; however, participation in the program is voluntary for patients’ families and friends. Some of these components (e.g., education and referral) may be available as parts of usual primary care in some practices, others are more particular to Guided Care and are therefore further described.

The first relatively unique feature is that the Guided Care Nurse meets with the family member or unpaid friend identified by the patient as assisting

<table>
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<tr>
<th>Outcomes</th>
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<td>Outcome measurement at 18 mos (n ~ 580 survivors, complete data)</td>
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**Patient**
- Functional ability
- Affect
- General health
- Satisfaction with care
- Use/cost of health services
- Mortality

**Primary caregiver**
- Burden/benefits of caregiving
- Affect
- Satisfaction with care
- Use/cost of health services
- Financial status

**Providers**
- PCP satisfaction
- PC office environment
- GCN satisfaction

**Insurers**
- Volume of services
- Cost of services
- Quality of care
“the most” with health-related tasks. The first meeting lasts on average 30 minutes and has several objectives, including: (1) to begin a working relationship between the Guided Care Nurse and the patient’s informal supports, (2) to allow the patient’s family or friend to state their own needs or concerns, and (3) to identify and facilitate relevant education and community services referral. Summary information from the meeting and intake form is entered into patient’s EHR and evidence-based care plan.

Each nurse also facilitates a Workshop once a week for six weeks, followed by ongoing monthly Support Group meetings, for any interested and involved families or friends of their patients. Each Workshop session is 90 minutes in duration and focuses on a particular skill, coping technique or issue related to assisting a chronically ill older adult. The Support Group meetings reinforce skills and techniques discussed in the Workshop, cultivate communication between nurses and families and friends of their patients, and provide families the opportunity to share their experiences and emotional support. Each Support Group decides for itself how to structure its time (e.g., whether to invite speakers) and when to hold the meetings.

Guided Care is a multifaceted model of care. To be successful, nurses must manage many responsibilities without letting any single function dominate. To this end, the Program for Family and Friends was developed to be flexible (e.g., the in-person meeting may be replaced by a telephone meeting for working caregivers) because some families or friends may not be able to fully participate in all aspects of the program. It is our hope that improved quality of patients’ health care in conjunction with more explicit recognition and support of their family caregivers will benefit patients, families, as well as valued patient care outcomes.

References


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The Veterans Health Administration (VHA) within the U.S. Department of Veterans Affairs provides routine health care services to 5.7 million veterans. Due in large part to the aging of the veteran population, the focus of care is shifting from acute to chronic conditions. While the general (non-VA) population is predicted to increase by 1.5 percent annually for people over age 65 and 2.2 percent for people over age 85, the group of veterans age 85 and older is predicted to increase 100 percent between 2000 and 2020, peaking at 1.3 million in 2012 (U.S. Census, 2001).

As with the general population, veteran patients prefer to live independently in their own homes and communities whenever possible. The VHA currently administers a number of services that support veterans and their families, including adult day care, respite care, case management and coordination, education and training of family members, transportation services, home care services and hospice. To meet the wishes of patients and accommodate these changing needs, VHA is rapidly expanding home-based services to care for those with chronic diseases. Services such as home-based primary care provide direct services in the home on a regular basis. VHA also has been exploring the use of new telehealth technologies to support care.

Care Coordination/Home Telehealth (CCHT). In July 2003, VHA established a National Care Coordination/Home Telehealth (CCHT) program to enhance and extend care and case management activities. The CCHT involves the use of health informatics, telehealth and disease management to enhance care management, facilitate access to care and improve patient health by providing the right care in the right place at the right time.

The benefits of managing patients with chronic conditions via CCHT are transforming outpatient services. Although the scheduled outpatient clinic is a cherished institution in the delivery of care, no existing evidence attests to its effectiveness, particularly in patients with chronic illnesses and conditions. Routine visits are often provided “just-in-case” a problem arises. All too often the patient deteriorates before or after the
regular clinic appointment. An alternative approach to the management of patients with chronic diseases is to see them “just-in-time” rather than “just-in-case.”

In introducing CCHT, VHA is reengineering its services based on this premise. Staff that are coordinating the care of patients use home telehealth technologies rather than rely upon clinic visits and hospital admissions. Patients who previously had many hospital admissions and emergency room visits show a 30 percent reduction in these episodes when enrolled into CCHT. While there is often an initial increase in the need for an ambulatory care clinic appointment when a patient is managed via CCHT, the need reduces over time.

**Patient and Family Caregiver Roles with CCHT.** The roles of the patient and the family caregiver in care self-management are critical to the success of CCHT. Care coordinators actively work with patients to help them understand their symptoms, acquire relevant knowledge and adjust behaviors to reduce the risk of their condition deteriorating.

The family caregiver is viewed as a vital partner: The presence of caregiver support in the home and local community has been a necessary inclusion factor for enrollment into CCHT programs. Moving the care of patients with chronic conditions into the home does potentially place a higher burden on the family caregiver. Understanding the impact on the caregiver of changes in the location of care and the critical role the caregiver plays in supporting care in the home has been of particular interest to VHA’s Office of Care Coordination (OCC) within the Office of Patient Care Services. Routinely the CCHT programs clinically assess caregiver support of patients and the needs of family caregivers themselves.

**Relationship to Other Caregiver Efforts.** The VHA has had a longstanding relationship with national caregiver organizations and initiatives in other federal agencies such as the Administration on Aging’s National Family Caregiver Support Program. Through a series of annual conferences commencing in November 2003, the OCC sought to highlight caregiver issues (e.g., caregiver assessment and local, state and national resources for caregivers) with a particular emphasis on CCHT. Attendees included representatives from national caregiver organizations, other federal agencies, veterans service organizations and CCHT.

**New Pilot Program.** In Fiscal Year 2007, the “Veterans Benefits, Health Care, and Information Technology Act of 2006” (Section 214, Title II of Public Law 109-46) requires VHA to carry out a pilot program to assess the feasibility and advisability of various mechanisms to expand and improve caregiver assistance services. The goal of the pilot program is
to encourage VHA providers to initiate new models of support services for caregivers in areas where such services are needed and where there are few other options available for families of disabled or aging veterans, particularly in rural or geographically-isolated areas.

The Office of Patient Care Services in VHA is actively engaged in implementing the pilot program for caregiver assistance. The Office is obtaining input from the range of other clinical services within the VHA for whom caregiver support is of particular importance, such as those serving veterans returning from Operations Enduring Freedom and Iraqi Freedom.

**Future Plans.** The innovative efforts of OCC within the Office of Patient Care Services to provide better support for families of veterans will continue. It is anticipated that, in the future, these pioneering approaches to improved recognition of and support for families of veterans will be incorporated into wider initiatives under development in the VHA, ones that will be taken forward under the stewardship of the Social Work Service.

**References**

U.S. Bureau of the Census (2001). Projections of the total resident population by 5-year age groups, race and Hispanic origin with special age categories: Middle Series, 1999 to 2010 (Table NP-T4).
Conclusion

Family Caregiving: State of the Art, Future Trends encompassed wide-ranging views, looking at family caregiving through the lenses of clinical and applied research, medical care, practice innovations, workforce, economics, culture, geography, advocacy and demographic trends. The 22 speakers offered unique insights and also found common ground in their recommendations for caregivers, providers, researchers and policy makers.

Themes and Insights

The cogent themes emerging across the presentations include insights on family caregivers as a whole in the U.S. and the risks caregiving places upon them; considerations particular to subsets of caregivers (women, rural, Latino, LGBT); structural issues in health care delivery that impact family caregiving; and lessons from successful interventions.

Family Caregivers in the U.S.

- Population-level data on caregivers suggest caregivers are slightly older than non-caregivers, more likely to participate in health promotion activities (exercise, monitor cholesterol, take a class to manage diabetes), but also more likely to have joint pain and to have had more days of poor health recently. Caregivers’ situations vary widely but a sizable share report stress, role captivity and lack of needed emotional support and help.

- Caregiver burden and health risks are increasing, as shown by the advancing age of caregivers, the higher disability levels of the persons for whom they are caring and the decreasing availability of other family members to help. A profound population-driven mismatch exists between the number of people needing care and
those available to provide it. Despite continued commitment to caring for aging parents, shrinking family size means burdens and costs of care will fall more heavily on fewer family caregivers in the future. Across the country, poor quality direct-care jobs result in workforce instability and labor shortages.

- For many family members, caregiving evolves into a chronically stressful experience that contributes to both psychiatric and physical illness and in some cases, mortality. The sources of stress include the functional disability and suffering of the care recipient, the work, frustrations and vigilant demands of caregiving, and secondary stressors such as financial problems and impaired family relationships. While the death of the care receiver often has a benign or even positive effect on the caregiver, placing a relative in a long-term care facility does not have the same impact.

- Costs of caregiving include loss of salary and benefits, loss of promotional and training opportunities, reductions in savings and investments, including lost opportunities for compound returns or 401(k) matching contributions, and an inability to finance home improvements to increase resale value of a home.

Special Groups of Caregivers

- **Women** generally need more retirement income than men because they live longer and therefore have greater exposure to chronic illness. However, female caregivers commonly do not make their own finances a priority – they use their own money for the care receiver’s daily needs, try to pay more than they can afford, and neglect saving for retirement because they are busy helping everyone else first (especially children and grandchildren). Middle-aged women who assume caregiving roles for their aged parents are 2.5 times more likely than non-caregivers to end up in poverty. Single women caregivers are four times more likely than married caregivers to end up in poverty in later life.

- **Rural** elderly rely even more on family and friends for assistance than do their peers in the cities or suburbs because rural areas have a higher proportion of older people and fewer health care and social service providers. Frequently the younger generation has left with no plans to return, leaving few to provide family caregiving. Elderly residents in small communities want the same right to age in place as those living in larger communities.

- **Latinos**, the biggest minority group in the U.S., tend to be younger and poorer than other groups, yet experience high rates
of chronic health conditions due to lack of access to health care and rigorous manual labor. Different subgroups of Latinos and immigrants have different levels of literacy—in Spanish and in English. Latinas and other women of color make up the vast majority of the direct care workforce.

- **LGBT** caregivers include individuals who self-identify as lesbians, gay males, straight transgender males and females, bisexual males and females, transgender lesbian and gay males, and transgender bisexual males and females. LGBT caregivers are similar to other caregivers but homophobia and heterosexism may add to their heavy load.

### Structural Issues

- Although chronic care now dominates medical practice in the U.S., traditional models are not effective for managing chronic illness; in the most effective and innovative models, patients and families are involved to a much greater degree. Effective outcomes in care settings depend upon knowing the risks and needs of both the person receiving care and the family caregiver. Embracing a family-centered perspective in health and long-term care and incorporating systematic caregiver assessment practices requires a fundamental shift in thinking.

- Most family caregivers are not integrated into the health care system that is serving their family member due to the focus of insurance and traditional medical practice solely on the patient, poor communications skills of providers and family members that break down trust, misinterpreted HIPAA privacy rules that leave families without crucial information, and the culture of medicine and health care that sees families as intrusive and time-consuming.

- No bright line exists between informal and formal care networks due to the shift of care for persons with chronic or disabling conditions from institutions to home, the proportion of direct care workers (up to 60%) who are themselves family caregivers and the consumer direction movement that is offering payment to more and more families to provide care. The family-paid caregiving continuum is a complex array, not two separate worlds. Paid direct care workers and family caregivers require similar skill sets and knowledge for successful caregiving; the hard work and contributions of both groups are often invisible to the larger society and taken for granted. Increasingly, we are depending upon an immigrant population to fill direct care jobs.
Technology is transforming the way families manage chronic illness at home—in rural communities and through the Veterans Health Administration. Health informatics, telehealth, web-based information, disease management approaches and various “gadgets” are becoming more widely available.

Lessons from Successful Interventions

- A social, ecological model, using a public health framework, can distinguish four levels that influence families and provide a better focus on what, when, where and how to intervene: (1) the individual person with impairment, (2) the caregiver and/or family system, (3) the organizational environment, and (4) national health policies for the society-at-large. Certain benefits are specific to the level at which the intervention occurs, e.g., targeting the care receiver may reduce objective burden on the caregiver yet not reduce caregiver depressive symptoms.

- Psychosocial interventions for caregivers generally improve psychological well-being; multi-component interventions are most effective; individually tailored interventions are more effective than group interventions; and interventions should be available for long periods of time.

- Persons with moderate cognitive impairment are willing to take responsibility for treatment decisions; families benefit most when the treatment goals and desires of both the impaired person and the family caregiver are mutually supported; caregivers who can discuss goals and preferences with their relative gain a better understanding of their relative and feel better prepared and less burdened to make care decisions.

- Recognizing that some individuals may not relate to the term “caregiver,” the term “families and friends” is being used whenever possible in a new lifetime model of care, designed to benefit chronic-care patients with multiple diagnoses, primary caregivers, providers and insurers (the Guided Care model).
Recommendations

For family caregivers, the speakers’ recommendations focused primarily on advocacy to change the system, but also included important advice to protect caregivers’ financial well-being.

Advocacy:

• Pay attention to health policy, particularly insurance coverage, and refuse to be shut out of the public debate. Get involved and recognize that no one else is going to put family care of the chronically ill on the agenda.

• Have reasonable alternatives for change; don’t just protest the status quo. Tie caregiving concerns to issues of current interest to the media—for example, raise questions about coverage for long-term care in federal and state level debates on health care reform. An effective caregiving story poses solutions and puts forth a call to action.

• Understand that caregivers are not the only game in town, but are competing for attention with many other valid interest groups who each believe their issues are the highest priority.

• Be persistent and pursue any opportunity, even if it takes longer than we wish, to make family caregivers an integral, properly compensated and supported part of our health care system. Changing the health care system in the U.S. is very difficult and occurs very slowly. We need sustained advocacy to progress further and faster.

• Unite to create a national consensus about universal access to essential services—where you live should not affect your ability to access services in times of greatest need.

• Work for policies that value families, whatever their configuration.

Financial Well-being:

• Before quitting a job to provide care, consider the impacts on Social Security (benefit is based on best 35 years of work and zeros are added for fewer years), on your employer-sponsored retirement plan (are you vested?) and on disability and health insurance (if you are hurt or ill), as well as the difficulty of re-entering the work force when caregiving responsibilities end.
For health care and service providers and for researchers, speakers offered suggestions for practice or areas of research to pursue and advice for advocacy:

Practice and research:

- Recognize that caregivers of older spouses and highly disabled persons need more support and assistance to help their family members or friends—of all caregivers, they are most likely to be going it alone without help from others or the formal system.

- Include both members of the care dyad in interventions for early-stage dementia.

- Offer to patients and families, through one source, a combination of successful innovations in self-management, decision support, use of clinical information systems and redesigned service delivery.

- Include counseling and support for families, along with prescriptions for medication in caring for people with dementia.

- Provide culturally competent services to reach the Latino community of caregivers.

- Carry out a cyclical process of reflection, advocacy, education and bridge-building at the individual, organizational and institutional levels to ensure optimal care and services to LGBT caregivers.

- Assume that both family caregivers and direct care workers will be users of high-tech devices being developed and design training for both.

- Assess the role of patient suffering in caregiver stress to deepen our understanding of caregiving and open new opportunities for caregiver interventions.

- Pursue further systematic research on caregiver interventions to identify innovative approaches for diverse populations and clinical conditions and translate tested, promising programs into everyday practices.

Advocacy:

- Be patient as you continue to advocate for families as care partners.

- Talk to federal and state officials about the central importance of assessing caregivers’ needs and helping families find the support that will keep them healthy and on the job, if they choose.
For *policy makers*—elected and appointed decision-makers at the local, state and federal levels who make the rules shaping the health care system, as well as others who control the purse strings—the speakers had far-reaching recommendations:

- Recognize the family as the unit of care.
- Make the integration of caregivers in the health care system standard, not exceptional, by increasing awareness, commitment and action among health care providers in hospitals, nursing homes and home health agencies.
- Recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities—include standardized caregiver assessment as a basic component in all publicly funded programs.
- Adopt public policies that support assessing and intervening with both care partners for early-stage dementia.
- Strengthen the linkages between formal and informal care networks through joint training programs, joint development of cultural competence programs and joint advocacy on long-term care financing, expanding family caregiver support and improving wages and benefits for direct care workers.
- Make closing the research-to-practice gap a priority.
- Combine proven approaches to chronic care management in one central source to create a sustainable intervention that can be diffused into practice settings throughout the health care system.
- Promote an integrated retirement policy that covers Social Security, employer retirement plans, savings and long-term care. Everybody can save, but not everybody can save enough for retirement.
- Advocate for and pursue new caregiving models that: (1) coordinate caregiving across settings; (2) integrate medical and social needs; (3) blend formal caregiving as needed with family and informal caregiving; (4) offer care-management frameworks that address the needs of care recipients and caregivers; and (5) value and support both paid and unpaid caregiving labor so that all caregivers can be respected and self-sufficient in their working years and in retirement.
Appendices

- A—Program Agenda
- B—Presenter & Moderator Biographies
- C—Conference Participants
Family Caregiving:  
State of the Art, Future Trends

Preconference Special Program  
2007 Joint Conference of the American Society on Aging and the National Council on Aging

March 6, 2007

Sheraton Chicago Hotel and Towers  
301 East North Water Street  
Chicago, Illinois

Presented by

The National Center on Caregiving, Family Caregiver Alliance  
In Partnership with The American Society on Aging

Sponsored by

The Jacob and Valeria Langeloth Foundation, The U.S. Administration on Aging,  
The John A. Hartford Foundation and The Caregivers Initiative, Johnson & Johnson

Program Agenda

8:30 – 8:45 a.m.  Welcome and Overview of the Day  
Kathleen Kelly, MPA, Executive Director, Family Caregiver Alliance

8:45 – 9:45  Opening Presentation

The New Meaning of Caring: Forces Reshaping 21st Century Health Care  
Emily Friedman, Independent Writer, Lecturer and Health Policy and Ethics Analyst, Chicago, IL

Although health care is always changing, the system and its patients are facing extremely powerful shifts in their environment. Among these are changes in the nature of the population, a growing desire by patients to control the circumstances of their care, reconfiguration of the health care system’s structure, a looming crisis in the provision and funding of long-term care and the vagaries of health policymaking. Family caregivers, the “safety net” for millions of patients, will be profoundly affected by these forces. Will that impact be positive or negative?

Questions and Dialogue

9:45 – 10:00  Break
Family Caregiving: State of the Art, Future Trends

10:00 – 12:00 p.m. Panel Presentation

Family Caregiving: State of the Art, Future Trends

Contrary to popular misconception, the primary source of care for people with chronic illnesses or disabilities in this country remains family and friends. The circumstances surrounding such caregiving have changed, however. A panel of distinguished leaders will explore the state of the art in family caregiving and highlight trends that will likely impact caregiving families in the future. Why is caregiving different now than in the past? What are the key challenges for family care in the decades ahead? How can we achieve a national commitment to strengthen and support America’s family caregivers?

Moderator: Jeanette Takamura, PhD
Dean and Professor, School of Social Work, Columbia University

Key Data Trends: Research on Caregiving Patterns and Characteristics
Brenda Spillman, PhD, Senior Research Associate, Urban Institute, Washington DC

Key Health Care System Trends: Families as Care Partners
Gregg Warshaw, MD, Professor & Director of the Office of Geriatric and Family Medicine, University of Cincinnati

Key Economic Trends: Baby Boomer Caregivers and Retirement Security
Cindy Hounsell, JD, President, Women’s Institute for a Secure Retirement (WISER), Washington DC

Key Technology Trends: Care Management Tools
Carol Smith, RN, PhD, Professor, University of Kansas Medical Center

Key Media Trends: Caregiving in Popular Culture
Robert Rosenblatt, Journalist, Washington DC

Questions and Dialogue

12:00 – 1:15
Lunch

1:15 – 3:00
Concurrent Workshops: Promising Practices and Research Trends

Caregiver Assessment: Filling the Gap in Policy and Practice

Moderator: Katie Maslow, MSW, Associate Director, Alzheimer’s Association
Lynn Friss Feinberg, MSW, Deputy Director, National Center on Caregiving, Family Caregiver Alliance
Susan Reinhard, RN, PhD, Co-Director, Rutgers Center for State Health Policy, Rutgers University

The value of systematic caregiver assessment is now on the public policy agenda. This interest stems, in part, from the fundamental need to improve direct supports for family caregivers and to focus on outcomes and quality of care for persons with chronic or disabling conditions. This session highlights consensus principles to guide caregiver assessment policy and practice, addresses myths and realities about including families in assessment processes, and identifies policy strategies to integrate assessment of family caregiver needs in programs and services. The presenters will discuss factors that facilitate and inhibit the adoption of these principles and guidelines in everyday practice.
Workforce Issues: The Link Between the Informal and Formal Care Networks

Moderator: Nancy Giunta, MSW, John A. Hartford Doctoral Fellow, University of California, Berkeley
Gail Hunt, President & CEO, National Alliance for Caregiving
Dorie Seavey, PhD, National Policy Specialist, Paraprofessional Healthcare Institute
Robyn Stone, DrPH, Executive Director, Institute for the Future of Aging Services, American Association of Homes & Services for the Aging

Family caregivers and direct care workers are the major providers of long-term care to older adults and younger persons with disabilities and chronic care needs. This session will provide an overview of the informal and formal caregiving populations, describe the demographic and economic trends affecting the demand for, and supply of, both family caregivers and direct care workers, and examine the ways in which informal and formal caregivers currently interface. Presenters will also identify current initiatives and explore an integrated policy and practice agenda to address the future demand for a quality long-term care workforce.

Caregiver Health: The Link Between Prolonged Stress and Illness

Moderator: Kathleen Kelly, MPA, Executive Director, Family Caregiver Alliance
Erin DeFries, MPH, Research Manager, Department of Epidemiology and Biostatistics, University of Florida
Richard Schulz, PhD, Professor of Psychiatry & Director, Center for Social & Urban Research, University of Pittsburgh

Family caregiving has emerged as an important public health issue. This session will provide an understanding of the links between the chronic stresses of caregiving and associated illness effects. Data from several large longitudinal studies will be presented to show how key caregiving transitions create or relieve stress and how changes in stress exposure are linked to physical and psychiatric morbidity, including mortality. Presenters will highlight the potential addition of a caregiver module to the Centers for Disease Control and Prevention’s Behavioral Risk Factor Surveillance System (BRFSS).

3:00 – 3:15
Break

3:15 – 5:00
Concurrent Workshops: Promising Practices and Research Trends

Diverse Caregiver Populations

Moderator: Donna Benton, PhD, Director, Los Angeles Caregiver Resource Center
Kimberly Acquaviva, PhD, Assistant Research Professor, School of Medicine & Health Sciences, George Washington University
Carmela Lacayo, President and CEO, Asociacion Nacional Pro Personas Mayores
Carol Miller, Director, National Center for Frontier Communities, Ojo Sarco, New Mexico

Today’s caregiving families are increasingly diverse. Program administrators and policy makers must recognize and address the needs of these diverse families across caregiver support programs and policies. This presentation will provide an overview of LGBT caregivers, Hispanic caregivers, and caregivers in rural and frontier communities and the unique challenges they face in accessing essential support services. Presenter will discuss strategies for increasing access to quality services for diverse caregiver populations.
Leading Edge Caregiver Interventions

Moderator: Vicki Schmall, PhD, Consultant in Aging Services
Laura Gitlin, PhD, Director, Center for Applied Research on Aging & Health, Thomas Jefferson University
Mary Mittelman, DrPH, Director of Psychosocial Research & Support, Silberstein Aging & Dementia Research Center, New York University
Carol Whitlatch, PhD, Assistant Director of Research, Margaret Blenkner Research Institute, Benjamin Rose

Recent caregiver intervention research has resulted in a vast array of promising approaches for supporting family caregivers, particularly for family members who care for relatives with dementia. This session will provide an overview of existing and emerging models of caregiver support services, highlighting specific examples of each and the evidence in support of their effectiveness with family caregivers. Presenters will also address the challenges of how to translate research findings into everyday practice with family caregivers.

Integration of Caregivers in the Health Care System

Moderator: Jodi Cohn, DrPH, Research Director, Geriatric Practice Innovation Research, SCAN Health Plan
Adam Darkins, MD, Chief Consultant for Care Coordination, Department of Veterans Affairs
Carol Levine, Director, Families & Health Care Project, United Hospital Fund
Jennifer Wolff, PhD, Assistant Professor, Department of Health Policy & Management, Johns Hopkins University Medical Center

Most family caregivers are not integrated into the health care system. Oftentimes, their circumstances are ignored in care planning, their requests for information denied, and their need for training and support unmet. This session will provide results from the United Hospital Fund’s “Inventing the Wheel” project, data from a nationally representative survey of Medicare beneficiaries, and a description of the Department of Veterans Affairs’ initiative to incorporate family caregivers into their care coordination program. Presenters will discuss implications for chronic care initiatives.

5:15 – 6:30 Reception and Networking
Family Caregiving:
State of the Art, Future Trends

Preconference Special Program
2007 Joint Conference of the American Society on Aging and the National Council on Aging

March 6, 2007
Chicago, Illinois

Presenter & Moderator Biographies

Kimberly D. Acquaviva

Kimberly D. Acquaviva, PhD, MSW is an Assistant Research Professor in the Department of Nursing Education at The George Washington University School of Medicine and Health Sciences. Dr. Acquaviva’s primary research interests are diversity, aging, and end-of-life issues, with a particular focus on lesbian, gay, bisexual, and transgender (LGBT) aging and end-of-life care. Dr. Acquaviva conducts research, workshops and presentations on end-of-life issues nationally and serves on the editorial board of the Journal of Gay and Lesbian Social Services as well as on The National Gay and Lesbian Task Force LGBT Aging Roundtable. She currently serves as Co-Chair of the American Society on Aging’s Lesbian and Gay Aging Issues Network (LGAIN).

Donna Benton

Donna Benton, PhD is a Research Assistant Professor of Gerontology at the University of Southern California (USC). Dr. Benton is also the Director of the Los Angeles Caregiver Resource Center at USC’s Andrus Gerontology Center. She works on caregiver research related to depression, stress, and program evaluation. Her publications focus on research in elder abuse and minority caregiving. She is also a licensed clinical psychologist.

Jodi Cohn

Jodi Cohn, DrPH is the Geriatric Practice Innovation Research Director at SCAN Health Plan. SCAN Health Plan provides comprehensive health care and a special package of in-home services to older people in Southern California. Her area of responsibility under Geriatric Practice Innovation is to research evidenced-based interventions in caring for older people and apply these practices to the components of the SCAN care management program. Her current areas of research are advance care planning, falls and care transitions. Prior to SCAN, she held positions in planning and evaluating health services for older people at the UCLA Borun Center for Gerontological Research, the UCLA Program in Geriatrics and Gerontology, UCLA Medical Center and the USC Andrus Gerontology Center.
Adam Darkins

Adam Darkins, MB, ChB, MPH, MD, FRCS is the Chief Consultant for Care Coordination in the Department of Veterans Affairs (VA). He was appointed to this position in 2003, having previously led the Telemedicine Strategic Healthcare Group in the VA since May 1999. Care Coordination in the VA involves the use of health informatics, telehealth and disease management technologies to enhance and extend care and case management. Under Dr. Darkins' direction, the VA is implementing telehealth-based services to support patients with chronic diseases in the home, address care coordination and support for family caregivers, screen for diabetic retinopathy, manage mental health conditions remotely and enable those wounded in combat who need rehabilitation to be cared for closer to home.

Erin DeFries

Erin DeFries, MPH is Research Manager for the Department of Epidemiology and Biostatistics in the College of Public Health and Health Professions at the University of Florida. Ms. DeFries works on a variety of projects funded by the Centers for Disease Control and Prevention to evaluate the impact of caregiving and disability on health status.

Lynn Friss Feinberg

Lynn Friss Feinberg, MSW is Deputy Director of the National Center on Caregiving at Family Caregiver Alliance (FCA). The Center works to advance the development of high-quality, cost-effective policies and programs for family caregivers in every state in the country. In recent years, she directed the National Consensus Project for Caregiver Assessment and the first 50-state study on caregiving programs in the U.S. Previously, she served for 16 years as FCA's Director of Research and Information Programs managing FCA's research, policy and clearinghouse functions and providing technical assistance to California's Caregiver Resource Centers. She is the author or co-author of over 50 publications and has served on numerous advisory committees and expert panels to address caregiving and long-term care issues. Ms. Feinberg is on the Board of Directors of the American Society on Aging (ASA), a member of the ASA's Generations Editorial Board, and a Fellow of the Gerontological Society of America. She is the recipient of the 2006 ASA Leadership Award.

Emily Friedman

Emily Friedman is an independent writer, lecturer, and health policy and ethics analyst based in Chicago. She is contributing editor of Hospitals & Health Networks and contributing writer for the Journal of the American Medical Association, Health Progress, and other periodicals. Ms. Friedman also serves as Adjunct Assistant Professor of Bioethics, Department of Health Law, Bioethics, and Human Rights at the Boston University School of Public Health, and is a consultant on information dissemination to the Agency for Health Care Research and Quality (AHRQ), U.S. Department of Health and Human Services. A prolific speaker, she has made many radio and television appearances and has lectured widely on health issues. Ms. Friedman has written or edited more than 700 articles, editorials or books in the past 28 years. She is most noted for her work in health policy, health care trends, health insurance and managed care, the social ethics of health care, health care for the underserved, and the relationship of the public with the health care system.
Laura N. Gitlin

Laura N. Gitlin, PhD is the Director of the Center for Applied Research on Aging and Health and Professor in the Department of Occupational Therapy, Thomas Jefferson University. Dr. Gitlin has numerous funded programs of research including developing and testing psycho-social-environmental interventions to improve physical function and well-being of older adults, and enhance quality of life of family caregivers and persons with dementia. In collaboration with community groups, she also has funded research programs on African-American mental health and aging, and chronic disease self-management. Dr. Gitlin has over 100 scientific publications in gerontology and occupational therapy, and has written and conducted workshops on innovative interventions to support families caring for persons with dementia.

Nancy Giunta

Nancy Giunta, MSW is a doctoral candidate at the University of California, Berkeley where her research is supported by a doctoral fellowship from the John A. Hartford Foundation’s Geriatric Social Work Initiative and the Center for the Advanced Study of Aging Services. Her research uses a mixed methods approach to examine the implementation of the National Family Caregiver Support Program in 50 states and the District of Columbia. She has over 15 years of experience in long-term care and caregiving settings. Most recently, she served as Project Manager of the San Francisco Partnership for Community-Based Care & Support. She now serves as a member of the program’s technical assistance consortium by providing assistance to current grantees in the area of program evaluation.

Cindy Hounsell

Cindy Hounsell, JD is the President of the Women’s Institute for a Secure Retirement (WISER), a nonprofit organization that seeks to improve the opportunities for women to secure retirement income and to educate the public about the inequities that disadvantage women in retirement. Ms. Hounsell provides technical assistance to several national organizations as well as training to leaders and grassroots advocates around the country as part of her role as director of the POWERCenter, the Program on Women’s Education for Retirement, a national resource center funded by the Administration on Aging. An experienced pension attorney, she has been widely quoted in the media and has written several chapters, columns, articles, op-eds, papers and booklets on women and retirement. Ms. Hounsell has testified before Congress and served as a delegate for a number of White House Summits and conferences.

Gail Hunt

Gail Hunt is President and CEO of the National Alliance for Caregiving, a non profit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. Previously, Ms. Hunt was president of her own aging services consulting firm for 14 years. She conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate eldercare program for employee assistance programs (EAPs) with the Employee Assistance Professional Association. In 2004, she was appointed by the White House to serve on the Policy Committee for the 2005 White House Conference on Aging.
Kathleen Kelly

Kathleen Kelly, MPA has been with Family Caregiver Alliance since 1979, and has served as Executive Director since 1990. She oversees programs of the Bay Area Caregiver Resource Center, which provides direct services to families and providers, the Statewide Resources Consultant, which provides technical assistance and consultation to the statewide system of Caregiver Resource Centers, and the National Center on Caregiving. Ms. Kelly has held seats on a variety of national, state and local advisory committees concerned with long-term care and public policy. Recently, Ms. Kelly has been focusing on the integration of information technologies into the nonprofit sector and in service delivery to FCA's clients through an Internet-based program of direct services to caregivers and a web-based client record system. She has lectured extensively on family caregiving, long-term care, advocacy, service delivery, information technology and nonprofit management. Ms. Kelly has authored or co-authored numerous articles and chapters on caregiving and information technology.

Carmela Lacayo

Carmela Lacayo, PhD is the founding President and CEO of the National Association for Hispanic Elderly, one of the largest national organizations serving the older Hispanic population through employment programs, other direct services, research, technical assistance, and bilingual media. During the past 30 years, Dr. Lacayo has raised and managed over $375 million dollars in funding for this organization. In addition, she founded El Pueblo Community Development Corporation, the first Hispanic economic development corporation in the city of Los Angeles. Dr. Lacayo has served as a member of several national advisory committees, including the Social Security Administration's Panel of Experts on the Supplemental Security Income (SSI) Modernization Project. In 1983, Dr. Lacayo was elected Chairperson of the Forum of National Hispanic Organizations, a coalition of 22 national Hispanic groups. She has also been named a Fellow of the Gerontological Society of America, becoming the organization's first Hispanic fellow.

Carol Levine

Carol Levine, MA joined the United Hospital Fund in New York City in 1996 where she directs the Fund's Families and Health Care Project. This project focuses on developing partnerships between health care professionals and family caregivers. Previously, she was director of the Citizens Commission on AIDS in New York City from 1987 to 1991 and director of the Orphan Project from 1991 to 1996. As a senior staff associate at The Hastings Center, she edited the Hastings Center Report. In 1993 she was awarded a MacArthur Foundation Fellowship for her work in AIDS policy and ethics. She has written and edited several books on family caregiving and has published numerous articles on the subject in professional journals, as well as in the popular press.

Katie Maslow

Katie Maslow, MSW is Associate Director for Quality Care Advocacy at the Alzheimer's Association. Her work at the Alzheimer's Association has focused on improving care for people with Alzheimer's and other dementias in managed care and hospital settings and increasing coordination of care between medical and community providers and settings. She is currently working on a project to increase the capacity of Aging and Disability Resource Centers (ADRCs) and other single point of entry systems to detect calls and contacts that pertain to a person with dementia, understand the implications of dementia for long-term care planning and service use, and provide appropriate assistance and referrals. In this and previous projects, Ms. Maslow has emphasized the critical role of families and other informal caregivers and the need for assessment of caregiver needs and provision of information and supports to meet those needs. Prior to coming to the Alzheimer's Association in 1995, Ms. Maslow was a policy analyst and senior associate at the U.S Office of Technology Assessment, a Congressional research agency.
Carol Miller

Carol Miller, MPH is the founder and Executive Director of the National Center for Frontier Communities, a national organization based in New Mexico. In addition she manages the projects and programs of the Picuris-Peñasco Community Coalition. In 1993, Ms. Miller served as a Presidential Appointee to the White House Health Care Task Force headed by Hillary Clinton. She was also a Presidential Appointee in the Reagan Administration where she was a Commissioned Officer in the U.S. Public Health Service. Previously, Ms. Miller was an Emergency Medical Technician for thirteen years, learning first hand about the health crisis as it affects individuals, families, and communities.

Mary Mittelman

Mary Mittelman, DrPH is Director of the Psychosocial Research and Support Program at the Silberstein Institute, a Research Professor in the Department of Psychiatry at New York University (NYU) School of Medicine and a leader of the Education and Psychosocial Cores of the NYU Alzheimer’s Disease Center. She is Principal Investigator of the NYU Caregiver Intervention Study as well as other studies of psychosocial interventions for people with cognitive impairment, dementia and their family members. Dr. Mittelman has published numerous articles on the results of the NYU Caregiver Intervention Study funded by the NIH since 1987 and, with her colleagues, has written several books for caregivers and health care professionals. Dr. Mittelman is a member of the scientific advisory boards of several Alzheimer’s Centers and research institutes.

Susan Reinhard

Susan Reinhard, PhD, RN is a Professor and the Co-Director of the Rutgers Center for State Health Policy. She is a national expert in long-term care, with special expertise in helping people manage their chronic disabilities at home. She currently works with more than 20 states to develop and fund new programs for home care and respite for family caregivers. In her previous work, she served as Deputy Commissioner for the New Jersey Department of Health and Senior Services, assisting three Governors to develop new programs for home care and respite for family caregivers. She also co-founded the Institute for the Future of Aging Services in Washington, DC and served as the Executive Director of its Center for Medicare Education. She is a former faculty member at the Rutgers College of Nursing and Chair of the Expert Panel on Aging at the American Academy of Nursing.

Robert Rosenblatt

Robert Rosenblatt is a Senior Fellow with the National Academy of Social Insurance, a national think tank dealing with Social Security, Medicare and related topics. He is also a website columnist on health policy issues and online forum administrator for the California HealthCare Foundation, as well as a columnist and editorial board chairman for Aging Today, a publication of the American Society on Aging. Mr. Rosenblatt is a former Washington correspondent for the Los Angeles Times.
Vicki Schmall

Vicki Schmall, PhD is the Executive Director/Gerontology & Training Specialist with Aging Concerns in West Linn, Oregon. She is also Professor Emeritus of Oregon State University (OSU), where she worked for nearly 25 years, serving as the Director of the Program on Gerontology and Gerontology Specialist in the OSU Extension Service. She developed the nationally disseminated program, Powerful Tools for Caregivers, a six-week self-care based education program for family caregivers. Dr. Schmall is the lead author of the book, The Caregiver Helpbook: Powerful Tools for Caregiving; she produced the video, The Many Faces of Caregiving; she developed a 7-module CD-Rom training program, C.A.R.E.-Pro, for the American Society on Aging to use in educating nurses, social workers and occupational therapists about family decisions and caregiving in later life; and developed 8 multimedia workshop packages focused on family caregiving decisions and communication.

Richard Schulz

Richard Schulz, PhD is Professor of Psychiatry, Director of the University Center for Social and Urban Research, and Associate Director of the Institute on Aging at the University of Pittsburgh. Dr. Schulz has spent most of his career researching adult development and aging and has been one of the leading contributors to the literature on Alzheimer’s caregiving. His research on Alzheimer's caregiving has appeared in major medical, psychology, and aging journals. He is also author of the Handbook on Dementia Caregiving: Evidence-based Interventions for Family Caregivers and served as principal investigator of the Coordinating Center for the NIH-funded REACH project, a major caregiving intervention trial. Dr. Schulz is the recipient of several honors, including the Kleemeier Award for Research on Aging from the Gerontological Society of America and the Developmental Health Award for Research on Health in Later Life from the American Psychological Association.

Dorie Seavey

Dorie Seavey, PhD, is the National Policy Specialist at the Paraprofessional Healthcare Institute (PHI). In this capacity, she supports PHI’s state policy directors and is responsible for research, analysis, and writing on economic, financial, and policy issues affecting the direct-care workforce and the long-term care industry. Her recent work addresses the cost of frontline turnover, strategies for improving wages and benefits for direct-care workers, the intersection of family and paid caregiving and reforming reimbursement methods for Medicaid home and community-based services. Trained as a labor economist, Dr. Seavey’s career has focused on workforce development and labor market difficulties for low-income individuals, including issues for frontline health care, social service, and childcare workers. She is a former Senior Research Scientist at the Heller School at Brandeis University.

Carol Smith

Carol Smith, PhD, is a Professor of Nursing an Adjunct Professor in Preventative Medicine and a Mentor for Faculty Research at the University of Kansas Medical Center. She has received 22 years of continuous funding from the National Institutes of Health (NIH) for her research endeavors with family caregivers of chronically ill persons requiring intensive care at home. Dr. Smith has numerous publications in nursing, medical and laymen journals. She was invited to present data, testimony and health policy information on family caregiving in 1996, 1999, 2001, and 2004 to the U.S. Department of Health and Human Services, NIH, Centers for Medicare and Medicaid Services and American Academy of Sciences in Washington, DC. In recognition for her research resulting in the improved quality of life for families managing complex chronic conditions, Dr. Smith was presented with the State of Kansas Research Achievement Award in 2004. Dr. Smith has also served as Fulbright Scholar to the University of Iceland and the University of Australia at Canberra.
Brenda Spillman

Brenda Spillman, PhD, a health economist, specializes in research on disability and long-term care use and financing among the older population, including the role of informal care in the long-term care system. She joined the Urban Institute as a Senior Research Associate in August 1998. Previously, she was a research fellow at the Agency for Health Care Research and Quality (then the Agency for Health Care Policy and Research) for 11 years. Her recent work includes studies on nursing home use and financing, long-term care insurance and public financing, trends in informal caregiving, impacts of informal care on nursing home use, and projections of service use and cost for the Medicare elderly. Dr. Spillman’s earlier work focused on the non-elderly uninsured, Medicaid, Medicare, and the impact of financing on health care utilization.

Robyn I. Stone

Robyn I. Stone, DrPH is Executive Director of the Institute for the Future of Aging Services (IFAS) at the American Association of Homes and Services for the Aging. She is a noted researcher and internationally recognized authority on long-term care and aging policy, and she has developed and directed a number of national programs including the Center for Medicare Education and the Better Jobs Better Care National Program. Dr. Stone has held several senior research and policy positions in both the U.S. government and the private sector, including serving in the U.S. Department of Health and Human Services as Deputy Assistant Secretary of Disability, Aging and Long-term Care Policy from 1993-1996 and as Assistant Secretary for Aging in 1997. Dr. Stone has published widely in the areas of long-term care policy and quality, chronic care for the disabled, workforce development and family caregiving.

Jeanette Takamura

Jeanette Takamura, PhD, is Dean and Professor at the Columbia University School of Social Work. She was Assistant Secretary for Aging in the U.S. Department of Health and Human Services during the second term of the Clinton Administration. Dr. Takamura led the Administration on Aging when the National Family Caregiver Support Program was designed and then enacted in 1999 along with the reauthorization of the Older Americans Act. Prior to her federal government appointment, she served as Deputy Director of Health in the State of Hawaii and Director of the Hawaii State Executive Office on Aging. Dr. Takamura has been involved in international expert exchanges and consultations on aging issues, including those organized by the United Nations and the World Health Organization. Dr. Takamura is a past-Chair of the American Society on Aging’s (ASA) Board of Directors.

Gregg Warshaw

Gregg Warshaw, MD is the Director of the Office of Geriatric Medicine at the University of Cincinnati College of Medicine. He is a professor in the Department of Family Medicine and the Martha Betty Semmons Professor of Geriatric Medicine. He is also Director of the Geriatric Medicine fellowship training program for physicians at the University of Cincinnati. Dr. Warshaw serves as Medical Director of Maple Knoll Village, a continuing care retirement community in Springdale, Ohio. Dr. Warshaw is Past President of the American Geriatrics Society and the Association of Directors of Geriatric Academic Programs. Recently, he served as editor of "Chronic Conditions in Later Life," the Fall 2006 issue of Generations, the journal of the American Society on Aging.
Carol J. Whitlatch

Carol J. Whitlatch, PhD is Assistant Director and Senior Research Scientist at the Margaret Blenkner Research Institute of Benjamin Rose. She has worked for over 20 years studying a variety of topics related to family caregiving including: developing and evaluating intervention strategies; choice and decision-making in caregiver-care receiver dyads; and autonomy and functioning in African-American caregiving families. She is an Adjunct Professor at Case Western Reserve University’s Mandel School of Applied Social Sciences, where she teaches graduate courses on family caregiving and advises graduate students. Dr. Whitlatch is Associate Editor of Dementia: The International Journal of Social Research and Practice.

Jennifer L. Wolff

Jennifer L. Wolff, PhD is an Assistant Professor of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health and holds a joint appointment in the Division of Geriatric Medicine and Gerontology at the Johns Hopkins University School of Medicine. Dr. Wolff's research is focused on how to best facilitate long-term care arrangements that afford older adults the opportunity to “age in place.” Most of her research is focused on understanding the roles that families assume to facilitate the medical needs of older adults and the potential quality of care implications of better integrating families by the medical community.
Family Caregiving:
State of the Art, Future Trends

Preconference Special Program
2007 Joint Conference of the American Society on Aging and the National Council on Aging

March 6, 2007
Chicago, Illinois

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