



Family Caregivers: The Primary Providers of Assistance to People with Functional Limitations and Chronic Impairments

BACKGROUND
PAPER NO. 84

CAROL V. O'SHAUGHNESSY, *Principal Policy Analyst*

JANUARY 11, 2013

OVERVIEW — An extensive body of research conducted over the past several decades has documented that family or other unpaid caregivers provide the majority of care to people who need assistance because of functional limitations or multiple and complex chronic conditions. Families play a central role not only in assisting impaired family members with personal care needs, but also in helping them coordinate health care and supportive services, and, increasingly, providing and/or supervising home-based medical care. This paper presents background information on family caregiving, briefly describes federal programs that provide direct assistance to caregivers, and discusses possible future policy and practice directions.

National Health Policy Forum

2131 K Street, NW
Suite 500
Washington, DC 20037

T 202/872-1390
F 202/862-9837
E nhpf@gwu.edu
www.nhpf.org

Judith Miller Jones
Director

Sally Coberly, PhD
Deputy Director

Monique Martineau
*Director, Publications and
Online Communications*

CONTENTS

Reliance on Family Caregiving 3

 What Is the Range of Assistance Provided to Adults with
 Disabling and Chronic Conditions by Family Caregivers?..... 5

 How Many People Provide Family Care?..... 10

 Has the Imputed Value of Informal Care Been Estimated? 11

 What Are the Effects of Caregiving on Caregivers? 11

 How Do Caregiving Responsibilities of Employed Caregivers
 Affect Business Productivity? 12

 What Effect Will the Aging of Society Have on
 Caregivers in the Future? 12

 What Federal Programs Provide Assistance to Caregivers?..... 13

 What Are Possible Future Practice and Policy Directions
 Related to Family Caregiving? 15

Endnotes 17

The National Health Policy Forum is a nonpartisan research and public policy organization at The George Washington University. All of its publications since 1998 are available online at www.nhpf.org.

Roughly 8 percent—an estimated \$207.9 billion—of all U.S. personal health care spending in 2010 went toward long-term services and supports (LTSS) for care of people with physical or cognitive disabilities provided by institutions and home- and community-based service providers.¹ This spending is for “formal care,” that is, for LTSS that are paid for by a third party, primarily Medicaid, and to a lesser extent by direct payments made by individuals and families, private insurance, and other public programs. The national spending amount does not reflect the value of care provided by families or friends who provide assistance to people with functional limitations or chronic impairments voluntarily, as a normal course of family life, and without monetary compensation. Family caregivers are the principal providers of such support and play a central role in coordinating health and social services for family members, and sometimes in providing or supervising home-based medical care. In this report, family caregiving refers to care provided by spouses, partners, children, siblings, friends, neighbors, and other unpaid caregivers.

RELIANCE ON FAMILY CAREGIVING

An extensive body of research, both from federally sponsored national surveys and special gerontological studies conducted over the past several decades, has documented that family or other unpaid caregivers provide the majority of care to people who need assistance because of functional limitations or multiple and complex chronic conditions. (Care provided by families and other unpaid caregivers is often referred to as “informal care.” See text box on terminology, next page.) Successive national surveys of the Medicare population age 65 and over living in the community with LTSS needs have shown that two-thirds rely exclusively on informal care.² Experts have described family caregivers as the “backbone” or the

Caregiver Terminology

Some experts have cautioned that the word “informal” is not appropriate to refer to the family caregiver workforce that is responsible for many essential LTSS and health-related tasks for their family members, such as personal care, medication management, assistance with medical equipment, and other health-related activities. They say the term “suggests casual, unstructured, unofficial care—pleasant but not essential.”

Carol Levine et al., “Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care,” *Health Affairs*, 29, no. 1 (January 2010): pp. 116–124, available at <http://content.healthaffairs.org/content/29/1/116.full.pdf+html>.

“bedrock” of the LTSS workforce.³ When faced with a disabling illness or condition, most people rely on care from family members who provide assistance without compensation or reimbursement. Most caregivers of older people with disabilities are women—primarily spouses, daughters, or daughters-in-law⁴—with the role of men increasing in recent years.

Reliance on family care is most often the preferred source of assistance for personal care and other tasks that are necessary for daily living. Beyond these activities, many people with chronic and disabling conditions rely on families to help them coordinate health care and supportive services, for example when they are discharged from a hospital or need care from multiple health care or LTSS providers. With more people living at home with serious and complex conditions, the range and intensity of care provided by family caregivers have grown. As care needs increase and families can no longer provide all the care needed—especially among those with complex conditions, Alzheimer’s disease or other dementias, or cognitive disabilities—formal care providers may supplement or substitute for family care. Such providers may include home care aides and/or adult day services, or, as a last resort, residential or nursing facility care. However, research shows that paid, formal care is not common. Even when paid care is used, many families continue to provide supportive assistance along with formal care providers.⁵

Congress has recognized the importance of providing assistance to caregivers through enactment of various federal programs. Some policymakers and practitioners have called for increased support to family caregivers to help them sustain their roles, citing their extensive responsibilities for family members with impairments as well as the often rudimentary and poorly organized caregiver support from public and private sources.

Gerontological literature describing and analyzing family caregiving roles and responsibilities dates back decades.⁶ Special surveys of caregivers of the Medicare population were conducted as part of the National Long-Term Care Survey (NLTC), a nationally representative survey fielded in various years since 1982.⁷ In addition to the NLTC, a number of national surveys on caregiving (either specifically on caregiving or as part of larger surveys) have been fielded in recent years.⁸ A successor to the NLTC, the National Health and Aging Trends Study (NHATS), along with a companion National Survey on Caregiving (NSOC), is under way.⁹

Research has documented various aspects of the caregiver role, such as the effect of caregiving on both employment and the health and financial status of caregivers, the type and range of caregiving tasks, and the time involved in caregiving, among other issues. In addition to this research, the Institute of Medicine (IOM) reported on the centrality of family caregivers as part of its larger 2007 study on building the health care workforce for an aging America.¹⁰

Even with a large analytic research base detailing the immense responsibilities of many families for care of family members with disabilities, it was not until 2000 that Congress specifically enacted a program to help caregivers as part of the Older Americans Act. Federal funding for the program is very modest at \$153.6 million for fiscal year (FY) 2012. (See section below on federal programs.)

What Is the Range of Assistance Provided to Adults with Disabling and Chronic Conditions by Family Caregivers?

Research has extensively documented the family caregiver role in helping family members with personal care activities and other tasks that are part of daily living. But family assistance goes beyond daily living tasks. Caregivers take on varied responsibilities for coordination and monitoring of LTSS and health care services, and sometimes also manage complex home-based medical care. Less well-documented is the role they play in helping family members who reside in residential care facilities.

Assistance with ADLs and IADLs —

Family caregivers often provide assistance with the most intimate personal tasks, such as helping a family member bathe, dress, get to the toilet and manage incontinence, eat, and get in and out of bed/chair [known as activities of daily living (ADLs)]. Families also help with other activities necessary for community living, including preparing meals, shopping,

Selected Resources for Family Caregivers

- The Eldercare Locator, a public service of the U.S. Administration on Aging, links people who need help with state and area agencies on aging and community-based organizations that serve older adults and their caregivers.
<http://eldercare.gov/Eldercare.NET/Public/Index.aspx>; 1-800-677-1166
- Family Caregiver Alliance and the National Center on Caregiving (NCC)
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368
- The National Alliance for Caregiving
www.caregiving.org/about
- The Caregiver Action Network
<http://caregiveraction.org/about/>
- The Rosalynn Carter Institute for Caregiving
www.rosalynncarter.org/
- AARP Caregiving Resource Center
www.aarp.org/home-family/caregiving/

managing money, housework, and laundry [known as instrumental activities of daily living (IADLs)]. Various national surveys have documented family roles in assistance with ADLs and IADLs; these include the NLTCs, the Health and Retirement Survey (HRS), and surveys conducted by the National Alliance for Caregiving (NAC) in collaboration with AARP.

The most recent survey completed in 2009 by the NAC/AARP found that 58 percent of caregivers of adults aged 18 and over assisted the care recipient with at least one ADL. Forty-three percent helped recipients get in and out of a bed or chair, 32 percent helped with dressing, 26 percent with bathing, 25 percent with toileting, and 19 percent with incontinence needs. A large majority of caregivers helped family members with IADLs: 83 percent helped with transportation, 75 percent with housework, 65 percent with preparing meals, and 64 percent with managing finances. Thirty-four percent of caregivers helped with making arrangements for and/or supervising paid services, such as nursing aides or meals on wheels.¹¹

Various surveys have estimated the amount of time that caregivers spend on assistance with ADLs or IADLs. Data based on the 2002 HRS showed that care recipients received, on average, 177 hours of family care per month—more than a full-time job for caregivers. Those with severe disabilities received an average of 289 hours of help per month.¹² The NAC/AARP survey found that family caregivers of adults spend an average of 18.9 hours per week in caregiving roles.¹³ While estimates of the type, range and amount of time spent in ADL/IADL caregiving vary depending on the survey methodology used, evidence points to very substantial effort, and research has shown that family caregiving can continue for years. The NAC/AARP survey showed that 34 percent of caregivers of adults had spent from one to four years in caregiving; 31 percent spent five years or more.¹⁴ Other research has shown similar patterns.¹⁵

Care Coordination and Transitions — A role of family caregivers that has gained prominence recently is their help to family members who are transitioning from hospitals to home, or to other settings, such as post-acute care in nursing facilities. One noted gerontologist, Eric A. Coleman, has pointed out that "... in the majority of care transitions, the patient and caregiver are the only common thread between sites of care and by default have been given the added responsibility of facilitating their care transitions, often without the necessary skills or confidence to do so."¹⁶ Another caregiving expert, Suzanne Mintz,

has pointed out that many families become care coordinators “by default” because in most cases current health care and LTSS delivery practices are not reimbursed for care coordination, and many caregivers are unprepared for this responsibility.¹⁷

Many factors may contribute to poor transitions, including lack of communication between hospital staff and family caregivers and between the hospital and formal community caregiver service agencies, absence of caregiver involvement in the post-hospital care plan, and poor or no post-hospital or nursing facility medical support. Poor hospital transitions often lead to poor patient outcomes and unnecessary hospital readmissions. While family caregivers assume tremendous responsibility for transitional care, Carol Levine of the United Hospital Fund and other experts say they are seldom involved in transition care planning, and “explicit attention to family caregivers is largely absent.”¹⁸ For some families, post-hospital care can be daunting, often leading to high levels of caregiver stress.

The Patient Protection and Affordable Care Act (ACA) of 2010 recognized the need to improve transitional care, with provisions to penalize hospitals for unnecessary readmissions for patients with certain diagnoses (acute myocardial infarction, heart failure, and pneumonia).¹⁹ The ACA also authorized grants to community-based organizations to help hospitals improve care transitions.²⁰ A number of models that have been advanced as ways to improve care transitions recognize the needs and strengths of family caregivers, including the Transitional Care Model and the Care Transitions Program.²¹ Another model, Next Step in Care, developed by the United Hospital Fund, provides a framework and extensive guide to help family caregivers and health care providers collaborate on planning and implementing transitions.²² Despite the availability of various models that engage family caregivers in transitions, a recent review found that they are not widely used by health care professionals. The review recommended increased attention to the needs of caregivers during care transitions in various policy and practice interventions.²³

Assistance with Complex Home-Based Medical Care — With shorter stays in hospitals under Medicare and Medicaid and the desire of many people with LTSS needs to reside at home rather than a nursing facility, family care at home for people with severe disabilities can be complex; in many cases, caregivers provide help to family members who need specialized equipment and who take multiple medications and therapies. Research has shown that families are taking on

an increasing range and intensity of services that formerly were provided by skilled and trained health care personnel.

Some family caregivers provide services similar to those provided in nursing homes and, in some cases, hospitals. They help family members with pain management, managing medical equipment, and elements of skilled nursing care, as well as coordinating medical and health care services and providers.²⁴ These health management tasks are often performed by families without preparation or training from health care professionals. A 2012 United Hospital Fund /AARP survey exploring the role that family caregivers play in providing complex chronic care found that almost half of caregivers performed medical/nursing tasks, such as providing wound care, using monitors, managing incontinence, or operating specialized equipment. About 78 percent of caregivers managed medication, including injections and intravenous therapy; 41 percent prepared food for special diets; 35 percent performed wound care; 32 percent used meters or monitors including glucometers to test blood sugar levels, oxygen and blood pressure monitors; and 25 percent managed incontinence, among other tasks. Caregivers who performed medical/nursing tasks were also likely to perform care coordination for care recipients. Many caregivers surveyed believed that by assisting family members with these services, they were helping them avoid nursing home placement.²⁵

Monitoring of Care Provided by Nursing Homes and Other Residential Care Facilities — Informal caregiving often continues once an individual becomes a resident of a nursing home, an assisted living facility, or other residential care setting. The increasing acuity of residents in nursing homes²⁶ and continuing concern about quality provided by facilities²⁷ often require family involvement to make sure that appropriate and adequate care is provided. Many families choose nursing homes based on proximity to their homes to facilitate frequent visits.

While various national organizations devoted to improving quality in nursing facilities stress the importance of family involvement in the care provided by nursing facilities,²⁸ extensive documentation of the extent and nature of family caregiving in residential care facilities appears to be lacking. The IOM study indicated that families who monitor care provided by facilities are underrepresented in studies of informal caregivers.²⁹ The NAC/AARP caregiving study shed some light on family visits to facilities. It indicated that more than three-quarters of families whose adult family members resided

in a facility (an independent living or retirement community, assisted living facility, nursing home, or group home) visited them at least once a week, with over half visiting more than once a week.³⁰

Anecdotal evidence shows that many families play an important role in monitoring care provided by facilities, advocating for improvements, and intervening with facility staff on behalf of residents. Some research has suggested that the family role is especially important to compensate when there is a perception of inadequate care provided by the facility.³¹ Other research has pointed out that families make efforts to monitor and manage the health and LTSS conditions of family members who live in assisted living facilities in order to prevent their discharge.³² (Assisted living facilities often discharge residents when they have care needs that the facility cannot provide.)

Number of Caregivers: Range of Estimates

A number of reports have identified numbers of caregivers. For example, an AARP report indicated that 42.1 million caregivers provided care to people with disabilities age 18 and over in 2009. This estimate was based on data from a national survey on caregivers conducted by the National Alliance for Caregiving and the Behavioral Risk Factor Surveillance Survey (BRFSS) conducted by the Centers for Disease Control and Prevention. (Lynn Feinberg *et al.*, “Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving,” AARP Public Policy Institute, Insight on the Issues, 2011, available at <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>). A National Alliance for Caregiving/AARP survey identified 48.9 million caregivers to people with disabilities age 18 and over in 2009 (“Caregiving in the U.S.,” executive summary, November 2009, available at www.caregiving.org/pdf/research/CaregivingUSAllAgesExecSum.pdf).

Some reports have provided reviews of estimates of the number of family caregivers and/or compared the methodologies of the various surveys. For example, see the Institute of Medicine, *Retooling for an Aging America, Building the Health Care Workforce* (Washington, DC: The National Academies Press, 2008), available at www.nap.edu/openbook.php?record_id=12089&page=241; Kirsten J. Colello, “Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress,” Congressional Research Service, January 29, 2009; Erin R. Giovannetti and Jennifer L. Wolfe, “Cross-Survey Differences in National Estimates of Caregivers of Disabled Older Adults,” *Milbank Quarterly*, 88, no. 3 (September 2010): pp. 310–349, available at <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-0009.2010.00602.x/pdf>; and Family Caregiver Alliance, “Side-by-Side Comparison of Family Caregiver Prevalence Studies,” fact sheet, December 2001, available at www.caregiver.org/caregiver/jsp/content/pdfs/fs_caregiver_stats_side_by_side.pdf.

How Many People Provide Family Care?

In its study of the U.S. health care workforce for an aging America, IOM stated that public policy has viewed family caregiving "...as a personal, moral obligation, and not as an extension of the [health care and LTSS] workforce..." and "[p]artly as a result, research has not provided a systematic accounting of their numbers, qualifications, and competence."³³ Despite the existence of a number of national surveys of family caregivers, differences in methodology make it difficult to draw definitive conclusions about the number of family caregivers (see text box). Some experts recommend that, in order to achieve clarity about the number of caregivers and the scope and outcome of their activities, standard definitions of family caregiving for federal and state surveys be developed.³⁴

Imputed Monetary Value of Family Caregiving

Studies of imputed value of caregiving have surfaced in recent years.

- A 1999 study for the United Hospital Fund estimated the imputed economic value of caregiving for adults age 18 or older at \$196 billion annually, based on 24 billion caregiving hours at a cost of \$8.18 per hour. Peter S. Arno, Carol Levine, and Margaret M. Memmott, "The Economic Value of Informal Caregiving," *Health Affairs*, 18, no. 2 (March 1999): pp. 182–188, available at <http://content.healthaffairs.org/content/18/2/182.full.pdf+html>
- In 2002, a study estimated the value of caregiving for adults age 18 and over at \$166 billion, based on 18.7 billion caregiving hours at a cost of \$9 per hour. Mitchell P. LaPlante, Charlene Harrington and Taewoon Lang, "Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home," *Health Services Research*, 37, no. 2, (April 2002): pp. 397–415, available at www.ncbi.nlm.nih.gov/pmc/articles/PMC1430364/
- In 2004, CBO released its analysis. Congressional Budget Office, "Financing Long-Term Care for the Elderly," April 2004, available at www.cbo.gov/sites/default/files/cbofiles/ftpdocs/54xx/doc5400/04-26-long-termcare.pdf
- A 2006 review estimated the economic value of caregiving from \$149 billion to \$483 billion, depending on the number of caregivers and hourly rates. Peter S. Arno, "Economic Value of Informal Caregiving: 2004," presented at the Care Coordination and the Caregiver Forum, Department of Veterans Affairs, National Institutes of Health, Bethesda, Maryland, January 25–27, 2006
- A 2011 AARP study estimated the imputed value of caregiving at \$450 billion based on 42.1 million caregivers providing care to people age 18 and over. Lynn Feinberg *et al.*, "Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving," AARP Public Policy Institute, Insight on the Issues, 2011, available at <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>

Estimates of the number of informal, unpaid caregivers vary widely depending on a number of factors, including the type and duration of caregiving provided, the age, disability status, and living arrangements of the care recipient, and whether the care recipient or the caregiver was interviewed to assess caregiving status, among other things. The IOM study stated that the "... most commonly cited figures indicate that there are between 29 million and 52 million unpaid caregivers nationally..."³⁵ One study that reviewed available surveys of caregiving estimated that the number of caregivers of older adults with disabilities ranged from an average of 4.8 million to 24.4 million caregivers, depending on the survey methodology.³⁶

Has the Imputed Value of Informal Care Been Estimated?

As a way to demonstrate the economic value of caregiving, some researchers have estimated the imputed value or cost of uncompensated family care with estimates ranging in the hundreds of billions of dollars. These estimates provide recognition that family caregivers are a part of the health care and LTSS workforce that otherwise would be overlooked. Imputed value is generally calculated by estimating the number of caregivers and caregivers' hours multiplied by an estimated dollar amount for the cost per hour of care from formal providers, such as home care aides. The Congressional Budget Office (CBO) estimated that the value of family care for the elderly in 2004 exceeded the amount of Medicaid LTSS spending in that year.³⁷

As with estimates of the number of caregivers, the range of estimates of imputed value varies widely depending on the number of caregivers counted, the ages and characteristics of the population being cared for, and the differences in methods used to calculate hourly rates for care provided. (See text box, previous page.) Regardless of the dollar amount assigned to an imputed value, public programs are unlikely to assume financial or programmatic responsibility for the type, range, and amount of care provided by family caregivers.

What Are the Effects of Caregiving on Caregivers?

Caregiving responsibilities often lead to physical, emotional, and financial strain for caregivers, some of whom are in poor health themselves. Gerontologists have documented the sacrifices that family caregivers make to care for family members.³⁸ A study for the U.S. Department of Health and Human Services (HHS) documented that high caregiver stress, especially physical stress, leads to a higher likelihood that the care recipient will enter a nursing home. In terms of effect of caregiving on family members, the study found that highly stressed caregivers were more likely to be in fair or poor health, provide larger amounts of care, provide care for older family members who require near constant supervision or exhibit behavior problems, and suffer financial hardship as a result of caregiving.³⁹

Because caregiving responsibilities often lead to physical and emotional stress, many experts consider the stress of caregiving to be a public health issue of growing concern. Inadequate public and private support for caregivers who provide significant amounts of care to family members with severe disabilities may lead to higher health

care costs for caregivers and possibly premature nursing home placement for care recipients, as well as financial vulnerabilities for those who leave employment to care for family members.

How Do Caregiving Responsibilities of Employed Caregivers Affect Business Productivity?

The NAC/AARP survey found that the majority of caregivers are employed,⁴⁰ and the HRS found that more than half of all adult children providing some care to older parents work full-time outside the home.⁴¹ Thus many people juggle caregiving with employment.

In 1997 and again in 2006, the MetLife Mature Market Institute estimated the productivity losses to U.S. businesses of employees who have caregiving responsibilities. Losses to businesses include costs associated with replacement of employees who must leave the workplace to perform caregiving, absenteeism, workday interruptions, unpaid leave, and reduction in working hours, among other things. MetLife estimated the costs associated with “intense” caregiving responsibilities, defined as helping family members with at least two ADLs and at least four IADLs for 12 to 87 hours per week. (Another measure was used to determine the effects of a less intense level of caregiving.) The estimated costs of productivity losses to employers were estimated at \$2.8 billion, or \$403 per employed caregiver with intense caregiving responsibilities, for replacing employees; \$3.4 billion, or \$489 per caregiver, for absenteeism; \$2.8 billion, or \$404 per caregiver, for workday interruptions; \$3.3 billion, or \$478 per caregiver, for conversion to part-time employment; and \$1.4 billion, or \$206 per caregiver, for unpaid leave.⁴² While a number of assumptions were made in order to determine these productivity losses, this analysis provides a framework for considering the effects of employed caregivers on the business sector.

What Effect Will the Aging of Society Have on Caregivers in the Future?

The aging of society is expected to exacerbate demands on family caregivers who may have to rely increasingly on formal, paid care to supplement their caregiving roles. One study estimated that 59 percent of people turning age 65 in 2005 will need family, or informal, care at some point in their lives; 35 percent will need such care for less than two years; and 23 percent will need such care for two to five

years or more.⁴³ Advances in health care have resulted in increased longevity of older people living with chronic illnesses or disabilities. These factors are expected to increase the extent and intensity of care and support needed.

Even though gerontologists expect that family care will continue to be the principal source of care for older people in the future, multiple demographic factors and changing family dynamics, such as lower fertility rates, smaller family size, more women in the workforce, and increased divorce rates, may result in fewer people available to provide caregiving.⁴⁴ At the same time, the increasing number of people with multiple chronic conditions may need the assistance of family caregivers to help them adhere to medication regimes, follow self-management protocols, coordinate care with providers, and help with medical care in the home. Some observers worry that the formal direct care workforce—paid staff who provide home care or care in residential care facilities—cannot keep pace with expected increased demand by a growing elderly population. The demand for personal care and home health aides is expected to increase by 71 percent and 69 percent between 2010 and 2020, respectively. These are among the top five fastest growing categories of occupations.⁴⁵

What Federal Programs Provide Assistance to Caregivers?

Congress has recognized the importance of focusing on assistance to caregivers of older people in several national programs as shown below.

- The Family and Medical Leave Act of 1993 requires private employers with at least 50 employees and public employers to provide job-protected unpaid leave to employees for various caregiving responsibilities, including care of an elderly relative. www.dol.gov/whd/fmla/
- In 2000, Congress enacted the National Family Caregiver Support Program as part of the Older Americans Act.⁴⁶ Services authorized include information and assistance about available services, individual counseling, organization of support groups and caregiver training, respite services to provide families temporary relief from caregiving responsibilities, and supplemental services (such as home care and home adaptations) on a limited basis to complement care provided by family and other informal caregivers. The number of caregivers served is about

600,000 annually. FY 2012 appropriations are \$153.6 million. www.aoa.gov/AoA_programs/HCLTC/Caregiver/index.aspx

- In 2006, Congress enacted the Lifespan Respite Care Act which authorizes the Secretary of HHS to award grants to states to develop respite care services and supplement or improve the access to them. FY 2012 appropriations are \$2.5 million. www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx
- Title VII of the Public Health Service Act (PHSA) authorizes funds for family caregiver training programs provided by Geriatric Education Centers.
- Other programs, such as the Medicaid home and community-based waiver program and the Social Services Block Grant (SSBG), primarily provide services directly to people with LTSS needs, such as home care and adult day services. These services indirectly benefit family caregivers. Both the Medicaid waiver program and the SSBG may provide respite services, and education and training for caregivers, at the option of each state. Spending on these programs is substantially larger than the direct caregiver support programs mentioned above.

These programs offer important assistance to some families but the scope of programs is generally quite limited. The IOM analysis stated that federal caregiver programs "...are generally small, poorly funded, and fragmented across the federal, state and local levels."⁴⁷ For example, the Older Americans Act and Lifespan Respite programs, administered by the Administration on Aging (AoA),⁴⁸ serve a relatively small number of caregivers compared with the estimated number of caregivers nationwide. The Older Americans Act caregiver program varies widely across states, and services are not generally comparable across local communities within states.

Generally very little evaluative data are available about the effect of these programs. A survey regarding the initial years of the Older Americans Act program implementation found that while the program had increased the range of caregiver support that state and area agencies on aging offer, major barriers cited were the need for better coordination of caregiver services with social services programs, the importance of developing methods to uniformly assess caregiver needs and provide caregiver training, and the need for additional funding for respite care services.⁴⁹ AoA is planning a national evaluation of its caregiver program.

What Are Possible Future Practice and Policy Directions Related to Family Caregiving?

Focus on Person- and Family-Centered Care in LTSS and Health Care Delivery — Given the primary role that family caregivers play in the delivery of LTSS and health care-related services, many practitioners believe that they should be explicitly recognized by providers as valued members of health care delivery teams. Some say that person-centered care should be coupled with family-centered care where families are integrated into care planning performed by physicians, nurses, social workers, and other professionals. Family-centered care recognizes and supports the role of family caregivers, addresses the needs of both the recipient of care and his or her caregiver, promotes communication and shared decision-making as well as coordination and collaboration by LTSS and health care delivery teams with family caregivers.⁵⁰ Building on these concepts, some are calling for “dignity-driven decision-making” for people with advanced illnesses that emphasizes the importance of a collaborative process where patients, their families and clinicians work together to define care goals and where families are full participants in care implementation.⁵¹

While these concepts have advanced in some advocacy, research, and practice circles, one national expert, Lynn Feinberg, reports that person- and family-centered care “...has not yet been fully integrated across the health care and LTSS systems as an essential part of all care and support.”⁵² As a result, some recommend that public policies and health care and LTSS practice protocols promote wider adoption of person- and family-centered care as an important way to improve care delivery.⁵³

Caregiver Assessment and Training — Some researchers, policy analysts, and practitioners are calling for more focus on caregiver assessment to determine how best to meet the needs of caregivers and recipients. This is viewed as an essential part of a care recipient’s care plan, especially when his/her care is dependent on a family caregiver.⁵⁴ Leaders in LTSS and health care delivery have reached consensus on fundamental principles and practice guidelines aimed at incorporating assessment of caregiver needs in everyday practice and service delivery settings, primarily by primary care physicians, and are calling for changes in policy and practice aimed at expanded support for family caregivers.⁵⁵ Assessment instruments, intended

to help practitioners evaluate caregiver needs, have been developed by organizations that advocate for greater caregiver support.⁵⁶

Some researchers are calling for more training for caregivers, especially for those who provide complex nursing and medical assistance to care recipients, and indicate that such training will require teamwork among all sectors: hospitals, home care agencies, community agencies, nursing homes, hospices, and clinical practices. Other recommendations call for development of curricula in medical, nursing, social work, and allied health professional fields order to strengthen training and support for caregivers as well as recognition of caregiver needs by accrediting and standard-setting organizations.⁵⁷

Beyond these recommendations, some policymakers are also calling for caregiver assessment and training. For example, legislation was introduced in the 112th Congress (S. 1819) that would amend the Older Americans Act to provide grants to states to develop standardized assessments of caregiver needs and appropriate caregiver support services. Another bill introduced in the 112th Congress (S. 2798) would have amended the Public Health Service Act to authorize grants for training and support services for Alzheimer's patients and their families. IOM has recommended that public, private, and community organizations provide funding for caregiver training opportunities.⁵⁸

Adjustments and Improvements to Health Care and LTSS Delivery Practices and Federal Caregiver Programs — Some researchers and practitioners are advocating that health care personnel give more recognition to the important role that caregivers play in the health outcomes of patients, and that health care models being developed under the ACA include recognition of caregiver needs for assessment, training, and ongoing support. For example, some experts recommend that the needs of family caregivers be "...explicitly included in proposals for transitional care and medical home programs, with appropriate funding and staffing."⁵⁹ Along this line, federal policymakers and state officials may want to consider how family caregiver protocols and policies could be adopted by new models of care and financing for dually eligible Medicare and Medicaid beneficiaries under the Centers for Medicare & Medicaid (CMS) care integration projects (<http://innovations.cms.gov/initiatives/State-Demonstrations/index.html>). For example, states implementing dual eligible demonstrations might determine the extent to which Medicare and Medicaid beneficiaries who participate in the demonstration have family

caregivers and how to effectively involve caregivers in implementation of the beneficiary plans of care. They might also consider ways to assess the needs of family caregivers, especially when they will be involved in plans of care, and how to offer continuing support to families who assume caregiving responsibilities.

Beyond care delivery improvements, adjustments may need to be made to existing federal caregiver programs. Given the relatively limited amount of funding for caregiver support programs, policymakers may want to consider how to better target services available under the Older Americans Act caregiver program in order to best meet family needs and produce outcomes that might result in more efficient and effective care for recipients. This might include, for example, development of protocols that would ensure that health care and LTSS practitioners coordinate recipients' care plans with family caregivers and that family caregivers are trained to carry out their caregiving roles, especially those who are providing care for those with complex medical conditions.

ENDNOTES

1. Carol V. O'Shaughnessy, "National Spending for Long-Term Services and Supports (LTSS)," National Health Policy Forum, The Basics, February 23, 2012, available at www.nhpf.org/library/details.cfm/2783.
2. Data are from the National Long-Term Care Survey (NLTC), a nationally representative survey fielded in various years since 1982. Special surveys of caregivers of the Medicare population were conducted in various years. Pamela Doty, "The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty Year Perspective," *Public Policy and Aging Report*, 20, no. 1, (Winter/Spring 2010): pp. 3-9, available at www.benrose.org/kpi/PP&AR_Vol20_%20No1_2010.pdf.
3. Jennifer L. Wolff and Judith D. Kasper, "Caregivers of Frail Elders: Updating a National Profile," *The Gerontologist*, 46, no. 3 (June 2006): pp. 344-356, available at <http://gerontologist.oxfordjournals.org/content/46/3/344.full.pdf+html>; Doty, "The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty Year Perspective"; Carol Levine *et al.*, "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care," *Health Affairs*, 29, no. 1 (January 2010): pp. 116-124, available at <http://content.healthaffairs.org/content/29/1/116.full.pdf+html>
4. Richard W. Johnson and Joshua M. Wiener, "A Profile of Frail Older Americans and Their Caregivers," Urban Institute, The Retirement Project, Occasional Paper No. 8, February 2006, available at www.urban.org/uploadedpdf/311284_older_americans.pdf.
5. Johnson and Wiener, "A Profile of Frail Older Americans and Their Caregivers."

6. See for example, Marjorie H. Cantor, "Strain Among Caregivers: A Study of Experience in the United States," *The Gerontologist*, 23, no. 6 (1983): pp. 597–604, available at <http://gerontologist.oxfordjournals.org/content/23/6/597.extract>; and Elaine M Brody, "'Women in the Middle' and Family Help to Older People," *The Gerontologist*, 21, no. 5, (1981): pp. 471–480, available at <http://gerontologist.oxfordjournals.org/content/21/5/471.extract>.
7. See the NLTC website, available at www.nltcs.aas.duke.edu/index.htm.
8. These include surveys by the National Alliance for Caregiving in collaboration with AARP (NAC/AARP, www.caregiving.org/research/general), the 2002 Health and Retirement Survey (<http://hrsonline.isr.umich.edu/>), and the Behavioral Risk Factor Surveillance Survey (BRFSS, www.cdc.gov/brfss).
9. See the National Health and Aging Trends Survey website, available at www.nhats.org/scripts/aboutNHATS.htm.
10. Institute of Medicine (IOM), "Patients and Informal Caregivers," chapter 6 in *Retooling for an Aging America, Building the Health Care Workforce*, (Washington, DC: The National Academies Press, 2008), available at www.nap.edu/openbook.php?record_id=12089&page=241.
11. NAC/AARP, "Caregiving in the U.S.," executive summary, November 2009, available at www.caregiving.org/pdf/research/CaregivingUSAllAgesExecSum.pdf.
12. Johnson and Wiener, "A Profile of Frail Older Americans and Their Caregivers."
13. NAC/AARP, "Caregiving in the U.S."
14. NAC/AARP, "Caregiving in the U.S."
15. Karen Donelan *et al.*, "Challenged to Care: Informal Caregivers in a Changing Health System," *Health Affairs*, 21, no. 4 (July/August 2002): pp. 222–231, available at <http://content.healthaffairs.org/content/21/4/222.full.pdf+html>.
16. Eric A. Coleman, "Falling Through the Cracks: Challenges and Opportunities for Improving Transitional Care for Persons with Continuous Complex Care Needs," *Journal of the American Geriatrics Society*, 51, no. 4 (April 2003): p. 550.
17. Statement by Suzanne Mintz, cited in Susan C. Reinhard, Lynn Feinberg, and Rita Choula, "A Call to Action: What Experts Say Needs to be Done to Meet the Challenges of Family Caregiving," AARP Public Policy Institute, February 2012, available at www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/Spotlight-Paper-Meeting-the-Challenges-of-Family-Caregiving-AARP-ppi-ltc.pdf.
18. Levine *et al.*, "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care," p. 122.
19. National Health Policy Forum, "Preventing Hospital Readmissions: How Can Care Transitions for Medicare Beneficiaries Be Improved?" Forum Session, October 28, 2011, available at www.nhpf.org/library/details.cfm/2874.
20. Centers for Medicare & Medicaid Services, "Solicitation for Applications: Community-based Care Transitions Program," available at www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/downloads/CCTP_Solicitation.pdf.

21. These include the Transitional Care Model at the University of Pennsylvania (www.transitionalcare.info) and the Care Transitions Program at the University of Colorado (www.caretransitions.org).
22. See the Next Step in Care website, available at www.nextstepincare.org.
23. Mary Jo Gibson, Kathleen A. Kelly, and Alan K. Kaplan, "Family Caregiving and Transitional Care: A Critical Review," Family Caregiver Alliance, October 2012, available at http://caregiver.org/caregiver/jsp/content/pdfs/FamilyCGing_andTransCare_CR_FINAL10.29.2012.pdf.
24. Carol Levine *et al.*, "Family Caregivers on the Job: Moving Beyond ADLs and IADLs," *Generations*, 27, no. 4 (Winter 2003–2004): pp. 17–23.
25. Susan C. Reinhard, Carol Levine, and Sarah Samis, "Home Alone: Family Caregivers Providing Complex Chronic Care," AARP and United Hospital Fund, October 2012, available at www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.
26. See discussion in Vincent Mor *et al.*, "Changes in the Quality of Nursing Homes in the US: A Review and Update," August 15, 2009, available at www.aqnhc.org/pdfs/changes-in-quality.pdf.
27. National Health Policy Forum, "Ensuring Nursing Home Quality: Continuing Challenges to Oversight and Enforcement of Nursing Home Reform," Forum Session, March 25, 2010, available at www.nhpf.org/library/details.cfm/2777.
28. See the website for the National Consumer Voice for Quality Long-Term Care, www.theconsumervoice.org/about; and the Long-Term Quality Alliance, "Person- and Family Centered Care," fact sheet, available at www.ltqa.org/wp-content/themes/ltqaMain/custom/images/LTQA_FactSheet_Patient-and-Family-Centered-Care.pdf.
29. IOM, *Retooling for an Aging America, Building the Health Care Workforce*.
30. Unpublished data based on survey data from "Caregiving in the U.S.," NAC/AARP, e-mail communication with author, July 5, 2012.
31. Marie-Luise Friedemann *et al.*, "Family Involvement in the Nursing Home: Family-Oriented Practices and Staff-Family Relationships," *Research in Nursing & Health*, 20 (1997): pp. 527–537.
32. Mary M. Ball *et al.*, "Managing Decline in Assisted Living: The Key to Aging in Place," *The Journal of Gerontology, Series B Psychological Sciences and Social Sciences*, 59, no. 4 (July 2004): pp. S202–S212.
33. IOM, *Retooling for an Aging America, Building the Health Care Workforce*, p. 247.
34. Lynn Feinberg *et al.*, "Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving," AARP Public Policy Institute, Insight on the Issues, 2011, available at <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>.
35. IOM, *Retooling for an Aging America, Building the Health Care Workforce*, p. 248.

36. Erin R. Giovannetti and Jennifer L. Wolfe, "Cross-Survey Differences in National Estimates of Caregivers of Disabled Older Adults," *Milbank Quarterly*, 88, no. 3 (September 2010): pp. 310–349, available at <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-0009.2010.00602.x/pdf>.
37. Congressional Budget Office, "Financing Long-Term Care for the Elderly," April 2004, available at www.cbo.gov/sites/default/files/cbofiles/ftpdocs/54xx/doc5400/04-26-longtermcare.pdf.
38. See for example, Brody, "'Women in the Middle' and Family Help to Older People," and Cantor, "Strain Among Caregivers: A Study of Experience in the United States."
39. Brenda C. Spillman and Sharon L. Long, "Does High Caregiver Stress Lead to Nursing Home Entry?" prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, January 26, 2007, available at <http://aspe.hhs.gov/daltcp/reports/2007/NHentry.pdf>.
40. NAC/AARP, "Caregiving in the US."
41. Johnson and Wiener, "A Profile of Frail Older Americans and Their Caregivers."
42. MetLife Mature Market Institute and the National Alliance for Caregiving, "The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business," July 2006, available at www.metlife.com/assets/cao/mmi/publications/studies/mmi-caregiver-cost-study-productivity.pdf.
43. Peter Kemper, Harriet L. Komisar, and Lisa Alexih, "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry*, 42, no. 4 (Winter 2005-2006): pp. 335–350, available at www.inquiryjournalonline.org/doi/abs/10.5034/inquiryjrn1_42.4.335.
44. See discussion in Johnson and Wiener, "A Profile of Frail Older Americans and Their Caregivers"; IOM, *Retooling for an Aging America, Building the Health Care Workforce*; Feinberg *et al.*, "Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving."
45. Paraprofessional Healthcare Institute (PHI), "America's Direct-Care Workforce," May 2012, available at www.directcareclearinghouse.org/download/PHI%20Facts%203.pdf.
46. For further information, see Carol V. O'Shaughnessy, "The Aging Services Network: Serving a Vulnerable and Growing Elderly Population in Tough Economic Times," National Health Policy Forum, Background Paper No. 83, December 13, 2011, available at www.nhpf.org/library/details.cfm/2880.
47. IOM, *Retooling for an Aging America, Building the Health Care Workforce*, p. 260.
48. As of April 16, 2012, the U.S. Administration on Aging is part of the newly created Administration on Community Living.
49. Lynn Friss Feinberg *et al.*, *The State of the States in Family Caregiver Support: A 50 State Study*, National Center on Caregiving, Family Caregiver Alliance, in collaboration with the National Conference of State Legislators, 2004, available at http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1220.

50. See the Institute for Patient- and Family Centered Care, www.ipfcc.org/about/index.html; Lynn Feinberg, "Moving Toward Person- and Family-Centered Care," AARP Public Policy Institute, Insight on the Issues, March 2012, available at www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/moving-toward-person-and-family-centered-care-insight-AARP-ppi-ltc.pdf; Long- Term Quality Alliance, "Person- and Family Centered Care."
51. Bruce C. Vladeck and Erin Westphal, "Dignity-Driven Decision Making: A Compelling Strategy for Improving Care for People with Advanced Illness," *Health Affairs*, 31, no. 6 (June 2012): pp. 1269–1276, available at <http://content.healthaffairs.org/content/31/6/1269.full.pdf+html>.
52. Feinberg, "Moving Toward Person- and Family-Centered Care," p. 1.
53. See the Institute for Patient- and Family-Centered Care website, www.ipfcc.org/about/index.html; Feinberg, "Moving Toward Person- and Family-Centered Care."
54. Lynn Feinberg and Ari Houser, "Assessing Family Caregiver Needs: Policy and Practice Considerations," AARP Public Policy Institute, June 2012, available at www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/caregiver-fact-sheet-AARP-ppi-ltc.pdf.
55. Family Caregiver Alliance, "Caregiver Assessment: Principles, Guidelines and Strategies for Change. Vol. 1," April 2006, available at www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf.
56. Family Caregiver Alliance and the Benjamin Rose Institute on Aging, "Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners," second edition, December 2012, available at http://caregiver.org/caregiver/jsp/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf.
57. Reinhard, Levine, and Samis, "Home Alone: Family Caregivers Providing Complex Chronic Care."
58. IOM, *Retooling for an Aging America, Building the Health Care Workforce*.
59. Levine *et al.*, "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care," p. 122.