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# The Road to Recognition:

## *International Review of Public Policies to Support Family and Informal Caregiving*

POLICY BRIEF

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September 2003

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FAMILY CAREGIVER ALLIANCE®  
National Center on Caregiving

## ACKNOWLEDGEMENTS

This policy brief was prepared by Anne Montgomery, M.S. and Lynn Friss Feinberg, M.S.W. Anne Montgomery, currently a Senior Analyst in health care at the U.S. General Accounting Office, conducted comparative research on family caregivers in the United Kingdom and the United States as an Atlantic Fellow in Public Policy in 2001–2002. Lynn Friss Feinberg is the Deputy Director, National Center on Caregiving at Family Caregiver Alliance.

Gail Hunt, Executive Director, and Les Plooster, Program Associate, both with the National Alliance for Caregiving, reviewed this policy brief. The authors gratefully acknowledge Karen N. Kolb, M.S., Information and Policy Associate at FCA's National Center on Caregiving, for her valuable research assistance.

Funded by the Archstone Foundation.

The opinions expressed in this policy brief are those of the authors and do not necessarily reflect the views of the Archstone Foundation.

## ABOUT FCA

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.

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Accelerating global trends in aging are now prompting policymakers in many countries to closely examine the long-term care needs, values and preferences of frail elders and persons with disabilities. Evidence compiled by the World Health Organization (2003) shows why:

- ◆ The population aged 60 and over is expected to rise dramatically, from about 600 million persons in 2000 to 1.2 billion in 2025, reaching 2 billion by 2050.
- ◆ Today, about two-thirds of all persons aged 60 and over are living in the developing world; by 2025, it will be 75%.
- ◆ The very old (age 80 and over)—those most in need of long-term care—is the fastest growing population group in the developed world.

Concomitantly, recent policy developments in several countries reviewed here reflect a growing recognition of the pivotal role played by family members and friends who, as informal caregivers, voluntarily provide support to ill and disabled family members when a chronic condition, trauma or illness limits the person's ability to carry out basic self-care tasks (e.g., bathing, dressing, preparing meals). These caregivers also bear most of the financial, emotional and physical pressures associated with daily care.

The result is that some countries have implemented comprehensive long-term care policy frameworks joining the needs of persons with disabilities and frail elders with their caregivers, while others have adopted more incremental ap-

proaches that continue to evolve. In all countries, family members provide the bulk of long-term care, with studies estimating that 65% to 80% of long-term care is provided by informal caregivers, mostly women (Jacobzone, 1999; Stone, 2000).

Currently, the statutory recognition of family and informal caregivers and the availability of caregiver support services differ significantly among countries. These differences affect the resources and rights of frail elders and persons with disabilities living in the community, as well as the choices afforded to caregivers—in some cases raising questions about the economic and emotional opportunity costs of over-reliance on informal care. Recent policy initiatives have taken a broad view of community care by establishing multi-pronged programs for national, state, provincial, and/or private responsibility for long-term care for older persons and, in some instances, their caregivers (World Health Organization & Milbank Memorial Fund, 2000). These initiatives demonstrate differences from past discussions of caregiver support, which have sometimes been restricted by assertions that it is not necessary for government to pay for care that families provide for “free.” A related policy debate has centered on the concern that development of programs providing greater assistance to caregivers through respite and more flexible home care services could trigger greater usage of formal services and erode family caregiver support (Silverstein & Parrott, 2001). However, a review of major studies published on formal and

informal home care services since 1985 concludes that evidence for the “substitution hypothesis” issue is weak (Penning, 2002).

This policy brief highlights where family caregivers now stand in relation to public policies for long-term care. The six countries reviewed (Australia, Canada, Germany, Japan, United Kingdom and the United States) represent diverse philosophies and policies with regard to supporting and sustaining family care of frail elders and persons with disabilities. Also discussed are caregiver assessment, employment leave law and certain tax law provisions. This approach is intended to illuminate where formal and informal systems of long-term care and caregiver support intersect, and where gaps and limitations remain.

### **I. Home and community-based services systems are increasingly likely to include the role of caregivers in long-term care strategies for frail elders and persons with disabilities, and as individuals with rights to their own support.**

Initiatives targeted to caregivers are on the rise, as shown in the table beginning on page 10. However, family and informal caregivers are still not formally integrated into the planning and implementation of many programs that deliver long-term care services.

- ◆ Despite growing recognition of caregiving as a salient policy issue, services continue to be highly variable in the United States (U.S.). The lack of a cohesive support system continues to pose major barriers for caregivers who seek basic information and other forms of assistance. The *National Family Caregiver Support Program* (NFCSP), established in 2000, is the first federal law to acknowledge the needs of family members who provide support to older persons. While the program is a promising start in federal funding of caregivers’ services, additional resources and support are needed to meet the multifaceted needs of caregivers (Feinberg, Newman &

Van Steenberg, 2002). Some states, including California, New Jersey, Pennsylvania, Oregon, Washington State and Wisconsin, have developed caregiver support models that could be studied when additional federal caregiver support strategies are designed and financed (Feinberg & Pilisuk, 1999).

The Medicaid program is a critical component of long-term care coverage for millions of frail elders and persons with disabilities who have modest incomes or whose medical costs are catastrophic (Rowland & Tallon, 2003). Medicaid dominates long-term care spending in the U.S. today, and while home and community-based services (HCBS) waiver spending has risen over the last decade, spending on institutional care still dominates the program (Feder, Komisar & Niefield, 2000).

Medicaid’s greater emphasis on financing of nursing home care can result in restricted choices of HCBS and other community services and confusion about how best to arrange the limited options that are available. Thus, caregivers are often forced to weigh a loved one’s needs and desires against financial realities (Citizens for Long Term Care, 2001). Currently, core program services cannot be provided directly to benefit the caregiver (Smith, Doty & O’Keefe, 2000), although some states offer beneficiaries respite and other services that indirectly benefit caregivers as part of federally-approved Medicaid HCBS waiver programs. Additionally, consumer-directed care options are expanding under HCBS waivers and state-funded community programs, some of which allow beneficiaries to reimburse family and informal caregivers for personal assistance services. In states that enable consumers to direct their own services, the freedom to hire a family member, friend or neighbor is considered an important aspect of consumer choice and control.

- ◆ While **Australia** is similar to the U.S. in its rate of population aging, ethnic diversity,

geography and strong tradition of individual responsibility, the national government has taken a comprehensive approach to community care of frail elders and persons with disabilities (Scharlach, 2002). Caregiver support is now identified as the third integral component of a national strategy, alongside community care and residential care. Three factors have contributed to strengthening support for caregivers:

- The support of caregivers is measured in terms of delayed entry of frail elders and persons with disabilities into residential care, which saves public sector costs.
  - Organizations representing caregivers have gained greater influence in policy debates during the last decade. The influence accelerated with the release of a National Agenda for Carers<sup>1</sup> in 1996.
  - Support for caregivers reflects strong community values centered on intergenerational exchange and reciprocity, and a central focus on support of families in federal government social policy (Howe, 2001).
- ◆ In **Canada**, caregivers are eligible for support services, including limited respite, but are not officially recognized as clients in the Canadian health and social service system (Guberman et al., 2001). Caregivers do not yet generally play a major role in the design and delivery of community services, which are organized by province.
  - ◆ To address the financial burden of long-term disability and illness for persons in need, **Germany** adopted a mandatory long-term care system for all citizens, based on the principle of social insurance. The *Long-Term Care Insurance Act*, which overhauled a previous system administered by local govern-

ments, became fully operational in 1996. It established a comprehensive national system of institutional care and home services that can be provided either by professionals or through an unrestricted cash payment which may be used to reimburse family members who provide services to disabled relatives. Support provided by caregivers as “family care” counts towards a state pension, and caregivers are eligible for skills training and home visits, as well as up to four weeks per year of respite care. A major factor driving Germany’s long-term care reforms during the 1990s was concern about the increasing burden on families—and women in particular—as family caregivers, and the potential “care gap” due to rising female employment (Evers, 1998). To date, most recipients (72%) are cared for at home, and there is heavy reliance on family caregivers as the major care providers (Geraedts, Heller & Harrington, 2000).

- ◆ **Japan** also has a comprehensive Long-Term Care Insurance (LTCI) Program which covers all disabled elderly persons and is based on social insurance principles. Financing is derived from general revenues and mandatory payroll contributions for persons aged 40-64 and public pension deductions for individuals aged 65 and older. Decisions about community-based long-term care services are made at the national government level. Under the LTCI home care program, beneficiaries can purchase services from professionals, but not family members. However, caregivers are eligible for respite. With the passage of the LTCI Program in 2000, eligibility criteria for long-term care no longer takes into account the extent of informal care available to older persons. The law represents a radical change in a society where caregiving by women, largely daughters-in-law, has long been a social norm. Before the Second World War, Japanese civil law stipulated that the eldest son inherited the assets of the family,

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<sup>1</sup> In Australia and in the United Kingdom, the term *carers* is used for family and informal caregivers.

and that care for aging parents was the responsibility of the wife of the eldest son, i.e., the daughter-in-law. By the mid-1990s, caregiving had become a social policy issue, fueled by population aging that coincided with a decrease in Japan's capacity for informal care as women joined the work force in increasing numbers.

- ◆ Caregivers in the **United Kingdom (UK)** are well organized politically. The roots of the caregiver movement are intertwined with the feminist agenda of the 1960s and 1970s, when legislation resulting in cash benefits for caregivers was advanced and enacted. One of these pieces of legislation, the Carer Allowance, was recently linked with the government's voluntary "State Second Pension" program. More recent legislation has given caregivers and their organizations a stronger voice in many aspects of social services programs, which is where community-based long-term care services are organized and delivered by local social services authorities.

This legislation grew out of the Labour government's February 1999 National Strategy for Carers, a policy blueprint that has been implemented across the UK. The National Strategy's goals have been realized partly through administrative changes made at central government level to non-devolved social security benefits and pension policy, and partly through laws enacted by elected nation assemblies in England, Wales, Scotland and Northern Ireland with jurisdiction over devolved policy areas, which include health and social services legislation. The National Strategy features several key elements: provision of better information for carers about long-term care services, health and social services policy; support in the form of increased consultation and the planning and providing of community services; and improvements in care for carers. In the latter category is the Carers Grant program for "short break" respite services, which re-

ceived 325 million pounds (approximately \$580 million U.S.) in earmarked funding over the first five years in England. Nation governments in Wales, Scotland and Northern Ireland have subsequently created similar programs that fund short break services.

## **II. The ability of caregivers to be assessed for services in their own right varies among countries.**

Fundamental to the design of a long-term care system is how an individual's need for services is assessed. All countries use a screening and assessment process to determine whether frail elders and persons with disabilities should be admitted to institutional care, while assessment for community care is more variable (Merlis, 2000). However, assessment of a caregiver's own needs is still quite limited, despite the central role that families play in coordinating and providing long-term care support. Among the countries profiled here, only the UK has an explicit national mandate to assess caregivers.

An important issue faced by some home and community-based programs is whether the availability of informal care should be considered when allocating long-term care benefits. Germany, for example, decided not to include this factor in its assessments of older persons, making the policy choice that the availability of informal care should be irrelevant in distributing a social insurance benefit (Merlis, 2000). Additionally, Japan no longer takes into account the extent of informal care available to long-term care clients (Arai, 2000).

- ◆ In the U.S., Medicaid eligibility assessments may take into account the informal support available to a disabled or elderly person, but there is no concurrent or independent assessment process for caregivers. Similarly, the NFCSP does not call for uniform national standards for assessing caregivers' needs for services. Some state-funded programs (e.g., California's Caregiver Resource Centers) uniformly assess the needs and situation of the family

caregiver to examine caregiver outcomes and assure quality of care (Feinberg, 2002).

- ◆ Although **Australia** has been active in supporting caregivers for well over a decade, no government policy on caregiver assessment has been implemented. However, researchers and practitioners are testing methods to comprehensively assess family care. A briefer screening tool which aims to incorporate the caregiver's needs, skills and preferences into the assessment and care planning process for frail elders and persons with disabilities is being developed for community care (Rembicki & O'Connor, 2001).
- ◆ In **Canada**, caregivers' needs are not assessed—either at the point that an elderly or disabled person is assessed, or independently—in decisions made about delivery of community services. Provincially administered home care programs may take into account the amount of informal support available, as well as the older person's financial ability to supplement publicly-funded care (Guberman et al., 2001).
- ◆ In **Germany**, which has enacted a comprehensive long-term care social insurance program that includes supports for caregivers, the availability of informal care is not taken into account in assessments of frail elders and persons with disabilities. Individuals applying for long-term care services undergo a technical assessment that classifies eligible beneficiaries into three categories of care, based primarily on degree of impairment in activities of daily living (ADLs) and time needed for assistance with ADL tasks (Evers, 1998). In cases where a qualifying older person chooses to receive home care solely from family members via the program's cash payment option, the law requires that caregivers pursue training to improve the quality of care they provide. Family caregivers of beneficiaries classified at care levels I and II are visited by professionals at least twice a year, and those caring for level III beneficiaries, who have the highest needs, are visited four times a year. These home visits allow for caregiver assessment, counseling and regular follow-up (Geraedts et al., 2000).
- ◆ In **Japan**, assessments for long-term care services are standardized, with findings analyzed by a government computer program that classifies applicants into one of six levels (Campbell and Ikegami, 2000). Assessments of elderly persons requesting services under the LTCI Program are caregiver-blind; that is, they do not take into account the amount of informal care available. Instead, assessments focus only on the physical needs of the elderly person. There is no explicit assessment of the caregiver's needs and situation.
- ◆ In the **UK**, caregivers have the right to an independent assessment of their needs under legislation enacted in England and Wales, the *Carers and Disabled Children Act of 2000*, as well as in Scotland's *Community Care and Health Act 2002* and Northern Ireland's *Personal Social Services (Amendment) Act 2002*. These statutes fulfilled a promise made in the 1999 National Strategy and also built on a prior UK-wide law, the *Carers (Recognition and Services) Act 1995*, which granted caregivers the right to be assessed at the point that frail elders or persons with disabilities are evaluated. Funding of caregivers' services is not guaranteed under these statutes. Administrative guidance on how caregivers are assessed in relation to evaluations of frail elders and persons with disabilities can and does differ within the UK. Mandatory guidance issued in 2002 explicitly requires local social service authorities to include, as an element of the care plan, voluntary contributions a caregiver is willing to make to the support of a disabled relative. The guidance, which applies only in England, also delineates which publicly funded services will be provided (Department of Health, 2002).

### III. Population aging is impacting employers and working caregivers.

The financial impact of caregiving is most apparent for caregivers when it affects their ability to engage in and to perform effectively at work.

This is a key issue for women, who are the most likely to provide family care, and who are increasingly participating in labor markets in industrialized countries. Employment leave laws can temporarily help bridge the gap between supporting a disabled or elderly family member at home while maintaining a job. However, current laws generally do not address family income loss during leave periods.

- ◆ Enacted in 1993, the U.S. *Family and Medical Leave Act* (FMLA) was the first national policy designed to help working caregivers meet both their work and family responsibilities. It authorizes unpaid leave of up to 12 weeks per year for the birth or adoption of a child, or to care for oneself or a sick family member—a spouse, child or parent. Currently, FMLA applies only to firms with 50 or more employees, who must work at least 1,250 hours per year to qualify and have been working for the organization for one year or longer. Working caregivers effectively must negotiate time off with their employer, although they cannot be fired for taking FMLA leave, and their positions cannot be terminated under most conditions. In addition, employers are required to maintain health insurance for employees on FMLA leave. Since 1993, a number of states have enacted their own versions of the FMLA that are more generous than the federal law (i.e., that apply to smaller firms or that make leave available for support of in-laws, grandparents, and other groups).

In California, the nation's first *paid* family leave legislation was signed into law in late 2002. Beginning July 1, 2004, working caregivers will be able to take up to six weeks of paid family leave, receiving 55-60% of their salary up to a cap of \$728 per week, through a state-administered disability

a state-administered disability insurance program. The new law is 100% employee-funded through a payroll deduction at an estimated cost of \$27 per worker per year (Bell & Newman, 2003).

The U.S. also has a corporate eldercare assistance sector, primarily in large companies. Nearly half of the major U.S. corporations offer some form of eldercare assistance to employed caregivers, with dependent care spending accounts (38%) and resource/referral programs (33%) the most common (Hewitt Associates, 2002).

- ◆ Most employers in **Australia** permit some time off for family leave for caregiving, although it varies in each state and territory, depending on specific workplace agreements or human resource policies. Generally, under the federal *Workplace Relations Act of 1996*, employees can use up to five days of their accumulated sick leave per year to care for a member of their immediate family.
- ◆ In **Canada**, the federal government has signaled its intention to integrate family leave into the national unemployment plan, particularly for end-of-life caregiving. Currently, policy differs from province to province. For example, Quebec recently adopted new labor standard laws which give five days leave of absence for family caregiving, and the option of taking up to a two-year leave of absence without job loss for caregiving.
- ◆ In **Germany**, there is no formal program of family or medical leave for workers who are supporting a frail, ill or disabled parent or spouse. Guaranteed leave is available only for working parents caring for newborns and those whose spouse is unable to provide support in the care of an ill child (K. Besselmann, personal communication, May 7, 2003).
- ◆ **Japan** enacted a Medical Leave Act in 1991. Its definition of “family” specifically allows for leave to support parents-in-law, since his-



torically most caregivers in Japan have been daughters-in-law.

- ◆ The UK's *Employment Relations Act 1999* took a step towards supporting working caregivers, requiring employers to give employees time off during emergencies. However, no definition of a maximum amount of leave was included in the legislation, and the time off can be paid or unpaid, at the discretion of the employer. In practice, these rights are extremely limited for carers of adults, to only one or two days at the most, and only in emergencies (E. Holzhausen, personal communication, May 2, 2003).

#### **IV. Tax incentives in several countries provide a measure of financial relief to caregivers, in the form of either a tax credit or a tax deduction.**

In general, while tax deductions are useful for persons in higher-income brackets because they enable taxpayers to lower gross income before calculating tax liability, they offer little help to caregivers who must quit a job to cope with heavy care demands (McConnell & Riggs, 1994). Tax credits, on the other hand, are more likely to benefit lower-income taxpayers, because they enable workers to deduct an amount from taxes owed, and are often viewed as a more equitable form of tax relief for caregivers.

- ◆ The U.S. has several limited tax benefits that apply to some working caregivers. A nonrefundable credit, known as the *Dependent Care Tax Credit* (DCTC) is available to lower-income working taxpayers and those with earned income who provide at least 50% of a dependent's support, and live with the dependent. However, the DCTC is claimed mainly by working parents of children, rather than working caregivers providing support for an ill or disabled adult family member (Silverstein and Parrott, 2001), and since the credit is nonrefundable, its value to lower-income working caregivers is limited. Building on the DCTC, 26 states and the District of

Columbia offer dependent care tax assistance to families, generally calculated as a percentage of the federal credit. Ten states (Arkansas, California, Colorado, Hawaii, Iowa, Maine, Minnesota, Nebraska, New Mexico and New York) now have refundable tax credits, targeting those most in need of assistance. (Center for Policy Alternatives, 2003).

Another program, the *Dependent Care Assistance Program* (DCAP), permits working caregivers to exclude from gross income up to \$5,000 annually in employer dependent care assistance when determining their income tax liability. The excluded amount is not subject to employment taxes for the taxpayer or employer. This program is often funded through salary-reduction plans that enable employees to purchase dependent care assistance with pre-tax dollars. Both the DCTC and DCAP require that the dependent spend at least eight hours a day in the employee's home, be financially dependent on the employee and unable to care for him or herself. The co-residency requirements and other restrictions limit the usefulness of these benefits for employees caring for a disabled adult (Levine, 2003).

Individuals in the U.S. with earned income can deduct medical expenditures that exceed 7.5% of their adjusted gross income under the *Medical and Dental Expenses* tax deduction. Qualifying taxpayers can claim medical expenses incurred on their own behalf, for a spouse, and for a dependent residing in the same household. Medical expenses can include certain capital expenses associated with adapting a home, such as modifications made for a spouse or dependent, and qualified private long-term care insurance premiums. Although the latter provision can be helpful to some taxpayers, it is not designed to assist those who cannot afford to purchase private long-term care insurance (Feder, Komisar & Niefeld, 2000).

- ◆ **Australia** provides benefits primarily through a Carer Allowance and Carer Payment (see table, page 11), rather than through the tax system. Tax deductions are also available for private health insurance (Jenson & Jacobzone, 2000).
- ◆ **Canada** offers several tax credits that benefit caregivers directly or indirectly, including a \$400 nonrefundable tax credit (approximately \$291.40 U.S.) for low-income caregivers that also exempts them from paying a tax on goods related to caregiving responsibilities. For caregivers aged 70 and older, a recent credit included in the 2000 budget provides a “work service check” intended to subsidize the cost of hiring in-home personal care services (Guberman, 1999). Canada also has two nonrefundable tax credits, the *Infirm Dependent Tax Credit* (IDTC) and a *Medical Expenses Tax Credit* (METC). The IDTC is for taxpayers who support disabled family members who have been assessed as having a severe and prolonged mental or physical impairment, and who rely upon the taxpayer for support. This credit also includes a cap on the dependent’s annual income. The METC is for disabled individuals or their caregivers, and caregivers may claim expenses that exceed 3% of net income incurred on behalf of a dependent relative. Allowable medical expenses include certain adaptations to a vehicle or driveway, equipment and devices, payment to health professionals, and the costs of hiring part-time or full-time attendant care. However, the narrowly drawn eligibility criteria of the IDTC and the METC make them unusable by many Canadian caregivers (Keefe and Francey, 1999).
- ◆ In **Germany**, family caregivers may claim a deduction for incurred expenses associated with hiring help to care for a household member, either on a regular or a periodic basis, and which are not reimbursed elsewhere. Different caps apply to deductions for periodic care and regular care (Keefe and Francey, 1999).
- ◆ **Japan** has a limited tax credit for workers supporting a frail elder over age 70 (Twigg, 1996), which was in place prior to the implementation of the public LTCI program in 2000.
- ◆ The **UK** central government recently enacted legislation revamping tax credits for working families with and without children, and for persons with disabilities. But there is not yet strong interest in devising a tax credit that would fit the circumstances of many caregivers whose care demands are heavy and who do not have either dependent children and/or a disability or illness. Currently, the threshold for benefits that applies to workers without a dependent child and/or a disability is 30 hours of paid work per week, as compared to 16 hours per week for workers with children or a disability that disadvantages them in seeking and retaining work.

## Issues for the Future

This policy brief underscores the importance of family and informal caregivers in the evolution of community-based long-term care initiatives. Demographics show that as our societies age, the chances of becoming a caregiver in the 21<sup>st</sup> Century are increasing. In the UK, for example, a recent study found that for women, the chances of becoming a caregiver are 50% by the age of 59. For men in the UK, the chances of becoming a caregiver are 50% by the age of 74 (George, 2001).

Yet despite well documented costs to caregivers—in time, in stress, in work productivity and in their own health and economic well-being—family and informal caregivers are not yet fully integrated into the public systems responsible for delivery of home, community-based and residential long-term care. The role of family and informal caregivers as key partners in helping to support older relatives and persons with disabilities is also not yet universally understood. Moreover,

caregivers' own emotional, physical and financial struggles and needs for support, as well as their knowledge and expertise about disabled and elderly family members, often go unnoticed by health and social service professionals.

The U.S. has yet to develop a cross-cutting national strategy or initiative that clearly addresses the diverse needs of family caregivers, who are the most important source of care for older people. In Australia and the UK, such strategies have done much to promote public discussion and debate about family care issues. For example, the UK's 1999 National Strategy for Carers launched a multi-pronged initiative that continues to guide policymakers today, and led directly to dedicated funding for respite care, as well as increases in social security benefits for qualifying caregivers. Further, the National Strategy foreshadowed an initiative to bring caregivers into the UK's "State Second Pension" program by making caregivers who spend one or more years out of the workforce eligible for somewhat higher payments on retirement.

The imminent challenge facing the U.S. and other countries is the establishment of comprehensive, affordable and balanced long-term care systems that meet the needs, values and preferences both of persons who need ongoing help to function on a daily basis *and* family members who are their primary caregivers. The demographic "bulge" associated with population aging during the first three decades of the 21<sup>st</sup> Century will fuel additional changes in long-term care systems—changes that will inevitably impact families across many countries. Yet if long-term care policies do not also build in support for the "hidden patient"—caregivers of older or chronically ill relatives—they may ultimately have the undesirable effect of draining an essential resource (Stone, 2000).

A critical component of any long-term care system should include public policy principles that:

- ◆ Recognize and support family and friends who provide care;
- ◆ Incorporate and advance the roles, responsibilities and rights of family and informal caregivers across various long-term care settings; and
- ◆ Strengthen and build initiatives that are based on:
  - equity of access to information and assistance in seeking long-term care services;
  - routine assessment of caregivers' needs;
  - provision of training, respite, counseling and other caregiver support services;
  - compensation for caregivers who must take employment leave to support frail elders and persons with disabilities;
  - pension credits for caregivers who cannot work due to heavy care demands;
  - wider availability of tax incentives; and
  - cash payment options to defray the higher cost of goods and services that are associated with illness and disability.

The voices of caregivers in all countries clearly deserve to be heard in discussions about programs designed to address the physical, emotional and financial pressures associated with family care. Finally, caregivers—those who experience daily the limitations of home and community care services—have a major role to play in broader policy debates to redesign a quality, reliable and affordable long-term care system for our families and loved ones.

## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Cash Payments to Family Caregivers/Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>United States</b>				
<p>A partial national caregiver strategy is in place in the form of the National Family Caregiver Support Program (see next column). Overall, support for family caregivers is highly variable in the U.S., with states differing widely in their approaches to caregiving and services provided.</p> <p>Caregiver support initiatives, many of which are modestly funded or limited in scope, include direct services (e.g., counseling, respite care), financial compensation to family caregivers, tax incentives, and employer-based mechanisms (e.g., family and medical leave, private long-term care insurance, workplace programs).</p>	<p>The National Family Caregiver Support Program (NFCSP) was established in November 2000 under the Older Americans Act. The NFCSP provides formula grant funding to states and Area Agencies on Aging (AAAs) for provision of a range of support services, including respite care. Services include: information to caregivers about available services; assistance in gaining access to services; individual counseling, support groups and caregiver training; respite care; and supplemental services (e.g., home modifications) on a limited basis to complement care provided by caregivers. The NFCSP is funded at \$155.2 million in FY 2003.</p> <p>Eligible populations of caregivers include family members of persons age 60 and over, and grandparents and relative caregivers of children under age 18. Priority is given to those in greatest social and economic need and older caregivers of children under age 18 with developmental disabilities.</p> <p>Numerous states also provide limited respite services through state general fund programs, Medicaid home and community-based services (HCBS) waivers, and other state funding streams.</p> <p>The availability of respite care is highly variable from state to state and communities within states.</p>	<p>Federal Medicaid law permits compensation of family members who are not “legally responsible” (i.e., spouses, parents), and many states, under their Medicaid home and community-based services (HCBS) waivers or state-only programs, do pay family members to provide personal care and respite. Some state Medicaid programs, e.g., CA’s In-Home Supportive Services (IHSS) program, draw on state and local funds to reimburse immediate family members (i.e., spouses or parents).</p> <p>The “Cash and Counseling” Demonstration is a large-scale evaluation of the consumer-directed model. Operating in 3 states (AR, FL and NJ), the program gives Medicaid recipients a monthly cash benefit to manage and purchase their own personal care, including hiring family members. Those who hire family or friends must pay them at least minimum wage and pay employment taxes, thereby enabling the caregiver to accrue quarters of work towards Social Security benefits.</p> <p>The NFCSP permits direct payments to family members for the purchase of goods or services. Some state-funded caregiver programs (e.g., CA’s Caregiver Resource Centers) also permit payment to family caregivers to provide respite.</p>	<p>Pension credits and Social Security benefits are not yet available to family caregivers, who may have to cut back on work hours or quit their jobs due to caregiving responsibilities.</p>	<p>Medicaid, designed as a means-tested and joint federal-state entitlement, is the largest single payer for long-term care (LTC) in the U.S. The majority of Medicaid spending is on institutional care; only about 29.5% of Medicaid LTC spending is for HCBS.</p> <p>Medicaid services through the federal share of funds must address the recipient’s needs, but states can offer respite and other supports under Medicaid HCBS waivers, indirectly benefiting caregivers. There is no federal requirement that family members provide some minimum amount of care as a condition of eligibility under Medicaid. However, states can and do take into account the amount of informal care available to an individual.</p> <p>Limited, non-means-tested Medicare home health services are available on an entitlement basis to beneficiaries in need of primarily skilled care.</p> <p>Some state-funded programs offer HCBS to persons who are not eligible for means-tested programs like Medicaid, filling important gaps in LTC. Some of these programs also provide caregiver support services.</p>

NOTE: In some countries (e.g., U.S., Canada), the term *family caregiver* is used to refer to family members who care for older relatives or persons with disabilities, such as a husband who has suffered a stroke; a mother with Parkinson’s disease; a father-in-law with cancer. In other countries (e.g., Australia, UK), the term *carer* is typically used to describe such family care.

## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Cash Payments to Family Caregivers/ Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>Australia</b>				
<p>A formal national caregiver strategy is in place. In 1996, a National Agenda for Carers was developed by the Commonwealth of Australia, Department of Human Services and Health. Caregivers are considered an integral part of the aged care system. Some states/territories are now developing caregiver strategies.</p> <p>With the establishment of the national Home and Community Care Program (HACC) in 1984, caregivers were recognized as clients in their own right, and a range of services was developed to assist them in recognition of their contributions to supporting older persons and younger people with disabilities (Howe, 2001). Today, extensive support is provided to caregivers, including general community support services, a range of respite care options, information and counseling targeted specifically to caregivers, employment-related initiatives, and cash benefits.</p> <p>An expanded “Carer Support Policy” was recently proposed in a white paper written by Carers Australia, a national organization representing carers, calling for alignment of “care packages” for older people and their caregivers.</p>	<p>National Respite for Carers Program includes residential care in hostels, day centers and at home. Information on respite care is provided by 82 Commonwealth Carer Respite Centres. Carers Australia runs 8 Commonwealth Carer Resource Centres to help families access and purchase respite services. Up to 63 days per year of respite are allowed, and individuals can be asked to pay a maximum of \$25.08 Australian dollars (approx. \$16.40 U.S.) per day for respite in residential care homes.</p> <p>Funding for the National Respite for Carers Program has increased from \$19 million in 1996-97 to more than \$92 million Australian dollars (approx. \$60.1 million U.S.) in 2002-03.</p>	<p>See Carer Allowance.</p> <p>Consumer direction is not currently part of Australia’s approach to community care of frail older people or support for family caregivers.</p>	<p>The Carer Allowance is intended to provide some compensation for the extra costs of caring at home for an adult or child with a disability or chronic condition. The allowance is equivalent to 20% of the single-rate retirement pension, which is itself set at one-quarter of average weekly full-time earnings. The Carer Allowance is non-means-tested, nontaxable and has a co-residency requirement. Payment is \$42.65 Australian dollars per week (approx. \$27.88 U.S.).</p> <p>The Carer Payment, which is part of the Social Security system, is means-tested and set at the same level as the retirement pension; it is payable to anyone who is: caring for a highly dependent person; does not receive other Social Security or Veterans’ Affairs income support; and cannot maintain paid employment due to caring. Payment is \$210.20 per week (approx. \$137.40 U.S.). The benefit is considered too low to replace salaries, however (Merlis, 2000).</p> <p>About 58% of all primary caregivers receive either the Carer Allowance or Carer Payment (Scharlach, 2002).</p>	<p>Since 1983, a consistent federal objective has been to re-balance the system of long-term care from residential care towards community care.</p> <p>The HACC Program is jointly funded and administered by the federal government and the states. Recipients are responsible for co-payments equal to 20% of program cost. Services range from just a few hours of supportive services per month in the home (e.g., help with laundry, meals, transportation) to more extensive support (Howe, 2001).</p> <p>For individuals deemed to be “at risk” for residential care, more intensive packages of personal care, nursing care and continence management services are available that are coordinated by a case manager.</p>

## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Direct Payments to Family Caregivers/ Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>Canada</b>				
<p>No formal national caregiver strategy is in place, and support for caregivers varies across provinces.</p> <p>Policies and programs are generally aimed at persons with disabilities; caregivers are not official “consumers” of the health and social services system. Instead, Canada provides some support for caregivers via the tax system rather than through explicit recognition or direct support.</p>	<p>The Long-Term Care Act of 1994 authorizes funding for caregiver support services, including respite care.</p> <p>Availability of respite services and funding varies by province.</p>	<p>Most Canadian provincial programs providing health and family supports to children and adults with disabilities will not compensate family caregivers, but exceptions exist in four provinces: Quebec, New Brunswick, Nova Scotia, and Saskatchewan.</p> <p>Quebec allows disabled individuals to use up to \$600 per year (approx. \$440 U.S.) for purchase of respite services, which may be provided by family members.</p> <p>Ontario central government prohibits payment to family members providing care to children but is silent on payment to family members providing care to adults, since adult services are funded through Transfer Payment Agencies (Interministerial Committee on Compensation for Family Caregivers, 2002).</p>	<p>Pension credits and Social Security benefits are not yet available to Canadian caregivers, who may have to cut back on work hours or quit their jobs because of caregiving responsibilities.</p>	<p>The Long-Term Care Act of 1994 authorizes funding for a range of community services, including: personal support services (e.g., assistance with bathing, dressing, etc., plus provision of prescribed equipment); homemaking services (banking, preparing meals, etc.); professional services (e.g., nursing, social work, dietetics); and community support services (such as respite, counseling, training and provision of information to caregivers).</p> <p>Availability and types of community services, including limited caregiver supports, vary by province, with services and eligibility criteria established locally, as well as co-payments for services.</p>

## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Cash Payments to Family Caregivers/ Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>Germany</b>				
<p>No formal national caregiver strategy is in place, but a broad social insurance framework categorizes the Long Term Care Insurance (LTCI) Program, which builds in explicit policies to recognize and support family caregivers.</p> <p>Caregiver support may be provided in the form of home care services delivered by professionals to frail elders or persons with disabilities or as unrestricted cash payments for the LTCI beneficiary to pay a caregiver, such as a family member. Other supports include respite care, training and education, home modifications, and paying contributions to pensions for family members who provide substantial care.</p>	<p>Caregivers have a right to four weeks vacation per year, during which LTCI pays for respite services through short-term nursing home care or other arrangements (Evers, 1998).</p>	<p>Under LTCI, cash payments to caregivers who provide services are encouraged. Beneficiaries who qualify on the basis of functional assessment may elect to have services delivered by a family member. Payments are worth about one-half of the value of formal institutional services, with a monthly cap on hours of care that can be reimbursed (Cueller and Weiner, 2000).</p> <p>LTCI provides incentives for women in lower income brackets to act as caregivers (Dallinger, 2002).</p> <p>The cash payments are widely viewed as a mechanism to support informal caregivers rather than a means to purchase services (Weiner, 2003).</p>	<p>While the cash alternative (i.e., cash payment) under the LTCI Program is meant to support family-based care arrangements, it is designed to be a specific caregiver allowance.</p> <p>Under LTCI, family care counts towards a caregiver's pension, in recognition of the fact that caregivers often have to cut back on work hours or quit their jobs to provide care to their relatives.</p> <p>Pension credits are available to caregivers providing support for more than 14 hours per week (Schunk and Estes, 2001).</p>	<p>LTCI is a universal social insurance program for long-term care that became fully operational in 1996. Operated on a pay-as-you go basis, it offers institutional and community-based coverage on an entitlement basis, subject to carefully drawn functional assessment criteria. LTCI is financed with employer-employee contributions (1.7% of employees' gross income, with half paid by employer), and a minimum of 25% cost sharing is applied to individuals receiving institutional care services. Retiree contributions are split between individuals and a pension fund.</p> <p>In a recent survey of LTCI beneficiaries and caregivers, about two-thirds of respondents said the program encourages citizens to care for their relatives and that the system appropriately acknowledges family care (Geraedts et al., 2000).</p>

## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Cash Payments to Family Caregivers/ Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>Japan</b>				
<p>No formal national caregiver strategy is in place.</p> <p>The government's Long-Term Care Insurance (LTCI) Program is designed to provide comprehensive services to older persons who do not assume support will be provided by a family member.</p>	<p>LTCI Program offers respite care in institutions and in the home.</p>	<p>Cash payments to family members who provide personal care or other services to older relatives are not permitted under the LTCI Program.</p> <p>LTCI limits itself to the purchase of services by professionals only.</p>	<p>Universal pension system for everyone over the age of 20 is in place.</p> <p>No specific caregiver allowances or care benefits are in place.</p>	<p>The LTCI Program offers community services coverage on an individual entitlement basis, including extensive home help services to older persons, including those with mild disability. Half of total financing is through general revenue (split between national and local governments), and the other half is derived from two premiums, one shared by employees and employers, the other a pension deduction from retirees.</p>



## Current Family Caregiver Policy in Six Countries

Government Caregiver Support Strategy	Respite Care	Payments to Family Caregivers/ Consumer-Directed Care	Caregiver Allowances and Linkage to Public Pension Plans	Long-Term Care: Key Community-Focused Provisions
<b>United Kingdom</b>				
<p>A formal national caregiver strategy is in place.</p> <p>New Labour's February, 1999 "National Strategy for Carers" created a UK-wide policy blueprint for caregivers, producing new pension policy and increases in social security benefits that remain within the jurisdiction of UK-wide central government. The National Strategy also spurred enactment of social services legislation by elected nation assemblies in Scotland, Northern Ireland, Wales and England granting caregivers the right to an independent assessment of need.</p> <p>The Strategy also directly led to the creation of respite, or short break, service programs in all nations. For working caregivers, the Strategy called on employers to expand "flex time" on a voluntary basis for working caregivers.</p>	<p>The Carers Grant program in England and Wales, established in 1999, provides dedicated funding to local authorities for provision of respite services for disabled and elderly persons that allow caregivers to take a break. In England, the Carers Grant was recently revised to allow funding to be used for additional caregiver-related services; e.g., certain types of training.</p> <p>In England, the Carers Grant received funding of 325 million pounds (approx. \$580 million U.S.) over the first five years.</p>	<p>The UK-wide Direct Payments Act of 1996 prohibits disabled and elderly individuals qualifying for direct payments from reimbursing carers for provision of personal assistance except under exceptional circumstances. The Scottish Parliament enacted legislation in 2002 that may loosen this restriction with a provision that allows persons who are acting on behalf of people who are "incapable of giving...consent" to receive direct payments.</p>	<p>A non-means-tested social security benefit, the Carers Allowance, is currently set at 42.45 pounds (approx. \$69.50 U.S.) per week; receipt of the Carers Allowance is also subject to an upper earnings currently set at 75 pounds per week (approx. \$122.85 U.S.) and a minimum of 35 hours of direct support provided to a severely disabled person each week. Eligibility is determined according to rules established by central UK government.</p> <p>A means-tested social security benefit, the Carers Premium, is currently set at \$24.80 pounds per week (approx. \$40.62 U.S. per week). Carers Premium is intended to compensate low-income caregivers who are not otherwise eligible for income support benefits.</p> <p>Beginning in 2002-2003, receipt of the Carers Allowance for each year of full-time continuous caregiving is linked to a slight increase in state-funded pension benefits under the government's "State Second Pension" program. Caregivers receiving the Carers Allowance are also linked to the state's basic pension program.</p>	<p>Community Care Act of 1990 provides for most institutional and community LTC services to be delivered by local social services authorities. The National Health Service is responsible for a small portion of LTC that is deemed to be primarily medical in nature.</p> <p>Institutional care is means-tested at central government level, and takes into account both income and the value of an individual's primary residence. Provision of home and community care is subject to charges based on an individual's income; services can either be provided or commissioned by social services authorities. Funding for social services authorities is set annually by nation governments and distributed on a formula basis.</p> <p>"Free" nursing care that is delivered or supervised by an RN is provided in England and Wales on a non-means-tested basis within an annual capped budget. Scotland provides "free" personal care services on a non-means-tested basis to older people through social services authorities within an annual capped budget. Social services authorities in Northern Ireland traditionally do not levy co-payments for home services.</p>

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