

Third International Conference on

Family Care

Hosted by the National Alliance for Caregiving

October 12-14, 2002

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Conference Report



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Third International Conference on Family Care

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Contents

Page

- | | |
|-----------|--------------------------------------------------------------|
| 2 | Introduction |
| 3 | A Cross-National Comparison of Caregiving Policies |
| 7 | Family Caregiving: Shared Experiences Across Cultures |
| 10 | Next Steps |
| 12 | Appendix |



Introduction

On October 12-14, 2002, nearly 700 caregiving advocates and policy makers from 22 nations met near Washington, DC, to share their progress and concerns in empowering and supporting caregivers, and, most of all, to learn from each other. One-quarter of participants were from countries other than the United States—among them were delegates from the United Kingdom, the Netherlands, Sweden, Australia, Israel, France, Ireland, India, and Japan. A significant number came from developing countries such as Albania, Peru, and Bangladesh, countries that were not represented at the first two international conferences.

The shared concerns of conference participants set the context for discussions of the importance of focusing on the needs of caregivers. With the rapid graying of the global population and the increasing life spans of people with disabilities, family caregiving is a crucial, yet under-appreciated safety net supporting the health care systems of many nations. Family caregivers provide unpaid, or at best underpaid, services that keep the majority of the world's elderly and disabled out of institutional care. In the United States alone, family caregivers provide an estimated \$257 billion in free care annually. This compares with only \$32 billion per year spent for paid home care and \$92 billion per year for nursing home care. In the United Kingdom, carers¹ provide the equivalent of about US\$86 billion in free care, which is the same amount that UK taxpayers contribute annually for their universal health care system.

Family caregiving is an accepted responsibility among cultures across the world. But the rapid growth in the elderly population has come at a time when families in most industrialized nations are less equipped than before to provide such care. Families today are smaller, more geographically dispersed, and far more women—traditionally the family caregivers—are juggling work and childrearing along with their caregiving duties. Increasing life spans also means that families spend more years caring for their elders.

A few countries are more advanced than the rest in terms of providing money and other forms of support to caregivers, but it was clear that no country was adequately meeting the growing needs of this population. Several themes emerged from the conference that were common to most nations, no matter how evolved their policies:

- Caregivers the world over feel isolated and consistently fail to self-identify;
- Caregivers need to become more politically active; and
- More work is needed to better understand the roles of young people (under age 18) as caregivers, and their unique needs.

This report offers an overview of the conference discussion of the differences in caregiving policies between countries, in particular the seven countries that dominated the conference policy discussion: Australia, Canada, Israel, Japan, Sweden, the United Kingdom, and the United States. The report also offers highlights from various workshops that illustrate the common themes mentioned above.

¹The term “carer” is used in several countries, including the UK, and is equal to the term “caregiver.”

A Cross-National Comparison of Caregiving Policies

United Kingdom

Government Profile: The United Kingdom is a parliamentary democracy with devolved administrations in Scotland, Wales, and Northern Ireland. The extent of devolution² varies between the countries, but in essence health and social care are devolved responsibilities, while taxation, employment and social security are not. The population of the UK is 58 million. Of these, an estimated 7 million are carers. Carers UK has calculated that carers contributions to society are worth US\$86 billion a year. This is equivalent to the cost that UK taxpayers paid in 2000 to support their National Health Service. About 16 percent of the population is aged 65 and over. This is expected to increase to over 18 percent by 2020.

All medical services under the National Health Service, including hospital treatment, are free to all citizens. There are, however, charges for eye tests, dental care and prescription drugs. These fees are means-tested and older people and children are exempt. Charges for social services, including nursing homes, vary depending on the local authority, but are generally means tested. Nursing care in nursing homes is free throughout the UK. Long-term care is administered by local government, which controls access to state-supported community care services that can only be provided after a formal assessment is completed. Scotland has introduced free personal care for all elderly people whether in residential care or living at home.

Caregiver Income Support: Across the UK, the Invalid Care Allowance (ICA) is a means-tested cash benefit available for carers who provide at least 35 hours a week of support to someone who receives a disability benefit. ICA is provided to carers with weekly earnings that do not exceed US\$123—the equivalent of the lower earnings limit for National Insurance contributions. ICA is currently about US\$69 a week. Carers earn pension rights while receiving the ICA. Once carers reach age 65 they cannot receive both ICA and the state retirement pension.

Caregiver Services: Grant programs in all nations in the UK have been established to provide respite care for carers, no matter their income. Some local authorities means test and charge for respite, others do not. In England, US\$159 million will be distributed to local authorities in 2003/4 in the final year of the Carers Special Grant. Local authorities have been providing flexible breaks for carers after consulting with them about their needs.

Each country within the UK has now passed legislation, the Carers Recognition and Services Act, that requires local authorities to assess the abilities of individual carers at the carer's request, and to use that information when determining what services are to be provided to the disabled or older person. However, the local authority is not obligated to provide services to the carer, the government authorized no new money to develop these services, and local authorities can charge for them. The legislation in England (The Carers and Disabled Children Act 2000) also provides for cash payments for carers, so that they can purchase their own services.

United States

Government Profile: The United States is a representative democracy with a population of about 285 million. 22.4 million US households contain at least one caregiver. National health insurance (Medicare) is available to those ages 65 and older, but does not include coverage for

²Devolution shifts responsibility for certain services such as health and social services from the UK government to regional governing bodies. The Scottish Parliament, National Assembly for Wales and the Northern Ireland Assembly were created as part of the process of devolution developed by the current government.

long-term care, personal care, or outpatient prescription drugs. Nursing home care is available to low-income residents through the Medicaid program, which is administered jointly by the states and the federal government. In the United States, 12.5 percent of the population is age 65 and over; this rate is expected to increase to 16.5 percent by 2020.

Caregiver Income Support: Currently, the US has no national policy for providing income support to family caregivers. However, a small number of states are experimenting with using Medicaid to pay caregivers, including spouses and parents, for providing personal care to low-income beneficiaries who are functionally impaired. In Arkansas, for example, the average caregiver's allowance under this experimental program is about \$400 per month. Caregiver payment demonstration programs are underway in California, Pennsylvania, New Jersey, Arkansas, Florida, Michigan, Oregon and Washington. In addition, through the Family and Medical Leave Act, the federal government has mandated that employers (with 50 employees or more) offer workers up to 12 weeks of *unpaid* leave each year to care for a seriously ill parent, spouse, or child.

Caregiver Services: Established in 2000 under the Older Americans Act, the National Family Caregiver Support Program is a modestly funded program that gives grants to state and local Area Agencies on Aging (AAAs) to provide caregivers of individuals age 60 or older with services including counseling and training, support groups, respite care and help in accessing other support services. States can also elect to allow local AAAs to use program funds to make direct payments to family caregivers, and twelve states have elected to do so. The program was funded at \$141.5 million in fiscal 2002 and \$155.2 million in fiscal 2003. The law calls for priority to be given to clients with economic and social need, although no formal means test exists.

In the mid-1980s, some US corporations began to invest in employer-sponsored work-life programs, including corporate eldercare programs for caregivers of older people. These programs run the gamut from flextime and telecommuting, to information and referral, to worksite support groups, to geriatric care management. About half of larger companies now have these types of programs. Few companies have comparable programs for caregivers of children or adults with a disability. In addition, like the UK and Australia, the US has several national caregiver advocacy groups that do research, develop programs for caregivers, and advocate on their behalf.

Sweden

Government Profile: With a population of about nine million, Sweden has a publicly funded system for health care and long-term care and services, provided to all residents according to need. Currently, about 17 percent of the Swedish population is age 65 and older; this rate is expected to increase to about 21 percent by 2020. Today, Sweden and Japan have the proportionately largest elderly populations in the world.

Caregiver Income Support: Sweden's 290 municipalities have the option of providing two types of cash payments for carers. An attendance allowance is an untaxed cash payment that goes to the dependent, to be used to pay the carer. Each municipality determines their own eligibility criteria and payment allowances. The monthly payment can go up to about US\$550. In 2001, 4,980 individuals received the allowance.

The other option is the carers allowance—a salary provided to carers under age 65 by the municipality that is fully taxable and offers both pension and vacation benefits. The salary is the equivalent of what a personal care aide employed by the municipality would receive. Municipalities often resist offering the carer allowance as a first response to service needs, but the carers allowance works well for elderly persons living in remote areas. 2,140 individuals received the carer's allowance in 2001.

Sweden also has an employee leave program that covers workers' salaries for up to 60 days (at 80 percent of their income) if they must leave to care for a terminally ill family member.

Caregiver Services: In 1998 the Swedish government established a three-year plan, with US\$10 million annual funding, to develop a local infrastructure of services to support family caregivers. The plan funds local municipalities to set up caregiver resource centers that offer training, counseling, support groups, respite care, and other information and resources for family caregivers, including day programs for their disabled family members.

Israel

Government Profile: Israel is a parliamentary democracy with over six million residents. About 10 percent of the population is age 65 and older; this rate is expected to increase to nearly 14 percent by 2020. Israel's national health insurance law provides universal coverage for medical services and hospitalization (with co-payments required). Institutional and in-home long-term care insurance is available only to those citizens with incomes at or below 150 percent of the nation's average wage as part of Israel's National Social Insurance legislation. Government support for institutional long-term care is means tested.

Caregiver Income Support: Israel provides no direct payments to family caregivers; support is offered through a number of tax and worker compensation programs. Under the Worker's Dismissal Compensation Act, workers who must leave their jobs to care for a sick family member are entitled to full dismissal compensation (roughly equivalent to unemployment insurance in the US). In addition, under the country's sick leave law, workers are entitled to six paid leave days to care for a disabled family member. Finally, Israel offers a tax credit of up to US\$400 to care for an elderly dependent parent.

Caregiver Services: Services such as home nursing, personal care, day care centers, respite care and laundry services are needs-tested entitlements provided under the community long-term care insurance law that is part of Israel's National Social Insurance Act. The program provides 11 to 16 hours of weekly in-home help. Services are usually provided by nonprofit and for-profit organizations in the community.

Australia

Government Profile: Australia is a democratic federation with a recent history of commonwealth government support for family caregivers. Of its nearly 20 million residents, 12 percent are over age 65; this rate is expected to increase to over 18 percent by 2020. The country's national health insurance program offers free medical care and hospitalization to all. Federal subsidies for nursing home care are available to all on a sliding scale based on income; fees range from about US\$5,000 to US\$15,000 per year.

Caregiver Income Support: Australia offers two allowances for caregivers. The Carer Allowance offers a small cash benefit (about US\$6 a day) to all carers, regardless of income, who provide full-time care to family members who would otherwise require nursing home placement. The allowance is a recognition of caring responsibilities and is not intended to compensate for the costs of caring.

The Carer Payment is a means-tested support designed to help people who must forfeit paid work in order to care for a highly dependent person. The rate is the same as the federal Aged (retiree) Pension, which amounts to slightly more than the unemployment benefit.

Caregiver Services: Established in 1985, the Home and Community Care (HACC) Programme was created to maintain disabled people in their homes and shift care costs from institutions to communities. The program acknowledges the roles of caregivers, providing them respite care, information, counseling, and other services at home. Through this program, there are eight caregiving resource centers (in each of the eight states and territories) and 64 centers that arrange

and organize respite care for caregivers. HACC is a US\$1.1 billion joint commonwealth/state cost-shared program, with the federal Commonwealth providing 60 percent of funds.

Canada

Government Profile: Canada is a parliamentary democracy with a population of about 32 million. About 13 percent of its population is age 65 and older; this rate is expected to increase to 18 percent by 2020. National health insurance offers medical services and hospitalization for all citizens. In regard to nursing home care, while medical services provided in such facilities are covered by national health insurance, residents are charged for accommodations.

Caregiver Income Support: At the federal level, most support for personal care for the frail elderly comes through the tax system, either through tax credits or deductions. Disabled persons, or their caregivers, can get a partial subsidy for medical expenses under the Medical Expenses Tax Credit, or expenses for daily living under the Disability Tax Credit and Attendant Allowance. In 1998, a tax credit for low-income caregivers was instituted; it reduces federal income tax by up to US\$400 a year, and is available to caregivers with net incomes under US\$14,000 a year.

Caregiver Services: The availability of services such as meal preparation, home adaptations, and respite care differ by province. At the provincial level, New Brunswick pays disabled residents to hire an independent care provider, although family members cannot be hired. Quebec provides up to US\$600 a year for caregivers to purchase respite care, with no limitations on whom they hire.

Japan

Government Profile: Japan, a constitutional monarchy with a parliamentary government, has one of the largest elderly populations in the world. With over 126 million residents, about 17 percent of the population is age 65 or older. The portion is expected to rise to 26 percent by 2020. Japanese life expectancy is also the longest in the world (77 yrs. for men; 84 yrs. for women), which will put even more pressure on the nation's long-term care system. About half of elderly people in Japan live with their children, the highest rate of all industrialized nations.

Caregiver Income Support: Japan does not provide direct payments to family caregivers, but recently has undertaken relatively expansive initiatives to offer universal long-term care coverage (including home care benefits) and to build up its nursing home and home care services infrastructure.

In 2000, Japan established the Public Long-Term Care Insurance Law, a mandatory insurance plan for all citizens over age 40 that offers residential and in-home care, including personal care. The law is funded half by premiums and half by taxes. Monthly premiums, which average US\$20, are set on a sliding scale according to income. Beneficiaries are charged a 10 percent co-pay for services. The government pays for the premiums and co-pays of impoverished residents.

Caregiver Services: In 1989, the national government established the Gold Plan—a ten-year plan with numerical targets—to expand the numbers of nursing homes and bolster the long-term care work force in Japan. Due to Japan's nursing home and personal home care shortage, hospitals are still the main facilities offering long-term care. Along with the Gold Plan, health officials expect the supply of nursing homes and home care will expand rapidly because the availability of long-term care insurance will spark demand.

Family Caregiving: Shared Experiences Across Cultures

Feelings of Isolation

Conference participants acknowledged that even in countries with more advanced social policies for caregivers, the universal core experiences of caregivers still appear to be those of feeling isolated and unsupported. Without intervention, these experiences are inherent to the nature of caregiving, where the caregiver is usually confined to home and relied upon for the most basic functions of living such as dressing, feeding and toileting. Getting necessary support requires that the person providing care identify as a caregiver, and this process has its own inherent barriers. To identify as a caregiver is to consider one's own needs, which is often a difficult task for those submerged in a selfless role. And, as explained at the conference by a leading gerontological researcher, there are strong psychological reasons that often keep caregivers from acknowledging the role they have assumed. A new study by US caregiving organizations the National Family Caregivers Association and the National Alliance for Caregiving provides some clues for those trying to reach caregivers who do not self-identify and what terms to use in particular.

In examining a seven-year time frame for caregivers of older people, Professor Rhonda Montgomery, director of the Gerontology Center at the University of Kansas, explained that in the first few years, the caregiver does not want to identify their changed role, because they are not prepared to lose their identity with the patient as a spouse or adult child. In many cases, to do so would be to acknowledge a loss of a significant relationship.

According to Montgomery, the best time to help a caregiver identify their new role is "when there is a significant change in the caregiver context," which can be brought about by a decline in the patient's functioning or a critical lack of resources at home.

Self-identification is often an emotionally difficult process, but all agreed that it is a crucial step toward organizing a political voice for caregiver support services.

The Need for Political Action

As mentioned before, of the 22 countries represented at the conference, a number were more advanced in terms of providing either income support for caregivers, or having a local infrastructure of support services in place for them. But no country was found to be adequately meeting the needs of this growing population. Conference participants universally called for greater political advocacy to ease the financial and emotional burden of caregivers. Interestingly, advocacy goals differed across the countries, influenced by government type and cultural views regarding the nature of family responsibility.

For instance, as Haifa University law professor Israel Doron described, Israel is conflicted over the option of providing direct payments to caregivers. Current support for caregivers comes in the form of a modest tax credit and wage compensation for job leave, but these policies are not enough to financially support full-time caregivers. The culture is caught between the ancient Jewish code of law, which defines caring for elders as a moral obligation, and modern pressures of employment and longer lifespan. One cultural argument against paying caregivers is that

such a government policy would demean, and in effect, decrease, any feelings of family responsibility for elders.

Doron said that caregiver advocates in Israel should forward their cause by pursuing the argument that helping caregivers is an indirect way of ensuring that the elderly are properly cared

If we truly want to protect the legal rights of the elderly, then we have to protect the legal rights of their caregivers.

for. "If we truly want to protect the legal rights of the elderly, then we have to protect the legal rights of their caregivers. It's a tool to preserve the rights of the elderly themselves," he said.

In Australia, caregiver advocates have already secured the right to direct government payments, although many argue that payment levels, especially for the middle class, are too low. One of the newer areas of reform interest, especially in the state of Victoria, is in requiring hospitals to better meet the needs of caregivers when discharging patients into their care. Carers Victoria has been advocating that upon patient discharge, hospitals inform caregivers of patients' future needs and assess caregivers' ability to provide them. According to advocate Julie Nankervis, Carers Victoria lobbied the state government to include assessing caregivers' needs in setting performance measures for hospital discharge systems; Victorian hospitals discharge about 1.5 million patients annually, she said. "We have not been particularly successful, but due to our efforts the government got to know about the needs of carers," she said. Carers Victoria developed an information kit on caregivers' needs during hospital discharge that it distributed to all hospitals in Victoria, Nankervis added.

Caregiver advocates in Western Europe were advised to beef up their advocacy efforts towards the European Union (an economic and social policymaking board comprised of 15 western

Carer advocates . . . need to lobby their cause better.

European nations). The Union, which has set higher targets for labor market participation for European nations, has also begun to broach the issue of reconciling work and family needs, "but they have focused more on child care issues," said Marja Pijl, board member of the Dutch Carers' Association. "Carer advocates will need to lobby their cause better," she said.

In the United Kingdom, due to the tenacity of Carers UK, caregiver policies have improved, albeit incrementally. Reforms have occurred "due to member effort, energy, passion and anger that carers feel when they find themselves in their circumstances," said Carers UK Chief Executive Diana Whitworth. In the early 1990s advocates secured a modest payment for low-income full-time caregivers. In 1996, caregivers won the right to a government needs assessment when evaluating the home care needs of care recipients, but were unable to secure the right to services. In 2000, they won the right to receive services, but the government issued no money for services. "Legislation is always a compromise," noted Baroness Jill Pitkeathley, a Member of Parliament and former leader of Carers U.K. Commenting on these legislative battles, Pitkeathley said, "We didn't get everything we wanted . . . But carers now have legal rights, which gives

them infinitely more political power and visibility" than before. In fact, caregivers are now included on many government task forces that shape long-term care policies.

In her keynote speech to the conference, Pitkeathley offered the following five lessons caregiver advocates should apply in their work: be united; be prepared to compromise; be politically neutral; be patient; and know that there is always more to do.

Looking to the future, both Pitkeathley and Whitworth said that Carers U.K. is campaigning for higher caregiver payment levels (with the goal of setting payments at the level of the government's retirement pension), and for government quality standards for respite care. Finally, caregivers were cautioned that the marginalization of women in nations around the world could be hindering the political progress of caregivers. As National Alliance for Caregiving Executive Director Gail Hunt noted, caregiving has suffered from the same political sluggishness that other family issues—such as childcare and maternity leave—have faced. "Many say that until caregiving is no longer viewed as a women's issue, it won't get the attention it deserves," she said. Studies reveal that in the United States, men represent a significant portion of family caregivers. By some estimates, nearly 30 percent of informal caregivers in the United States are male.

Young Caregivers


A sobering reality in many of the countries represented at the conference is the significant presence of young people (in Australia, for example, defined as ages 6 to 18) who are primary caregivers for their parents who have a disability, chronic condition or mental illness. In Australia, for instance, while family caregivers can be found in about one in five of all households, about 10 percent of all 15-25 year-olds have been identified as caregivers, according to the 1998 national Disability, Ageing and Carers survey of the Australian Bureau of Statistics (ABS). According to

Many of the countries that offer some type of support to caregivers do not make these benefits available to young caregivers.

this survey, young caregivers were most often from low-income families and lived with only one parent. Parental mental illness was a significant reason for care, but most young people cared for someone with a physical illness or disability.

Adult caregiver advocates, as well as young caregivers themselves, described the heavy toll that caring takes on young people. They are less emotionally and financially equipped than adults to assume this responsibility, and in most of the nations represented, their circumstance is perceived as significantly disadvantaged. "There is a societal expectation that people will become carers when they age," said Beatrice Hale of Carers New Zealand. "But we don't expect this of our young," she added. Also, many of the countries that offer some type of support to caregivers—either direct payments or social support—do not make these benefits available to young caregivers.

Young caregivers discussed their experiences at several workshops. Julie Sengstock is an 18-year-old Australian girl who has cared for her mother, who suffers from schizoaffective disorder, for five years. "She was in and out of the psych hospital every two months. I constantly had to pick up the pieces of my mother's life," she said. Julie and other young caregivers described



how their caregiving responsibilities have kept them from becoming involved in many school activities and interfered with their ability to make and keep friends. They said they often felt isolated and poorly understood, especially by the school system and other students. "I always wanted a life that was normal," commented Anne, a 16-year-old caregiver from the Australian state of New South Wales.

The ABS data shows that young primary caregivers (ages 15-25) were less likely than their peers to stay in school or find employment. Four percent of young primary caregivers in this survey were still in school compared with 23 percent of other people their age. In addition, 60 percent of young primary caregivers between 15 to 25 years old were unemployed or not in the labor force, compared with 38 percent of their peers in the general population.


A number of regions, including some in Australia and New Zealand, have developed programs to address the needs of young caregivers. Sarah Henderson, a 17-year-old caregiver from New South Wales, described the caregiver's camp she has attended for the past two years as "the best times of my life." The camp, organized by Carers New South Wales, offers a variety of activities for young people including holiday camps, telegroup counseling programs, and advocacy on their behalf. According to Sarah, camps allow her to develop a strong network of friends facing similar circumstances. "Young carers see that they're not alone," she said.

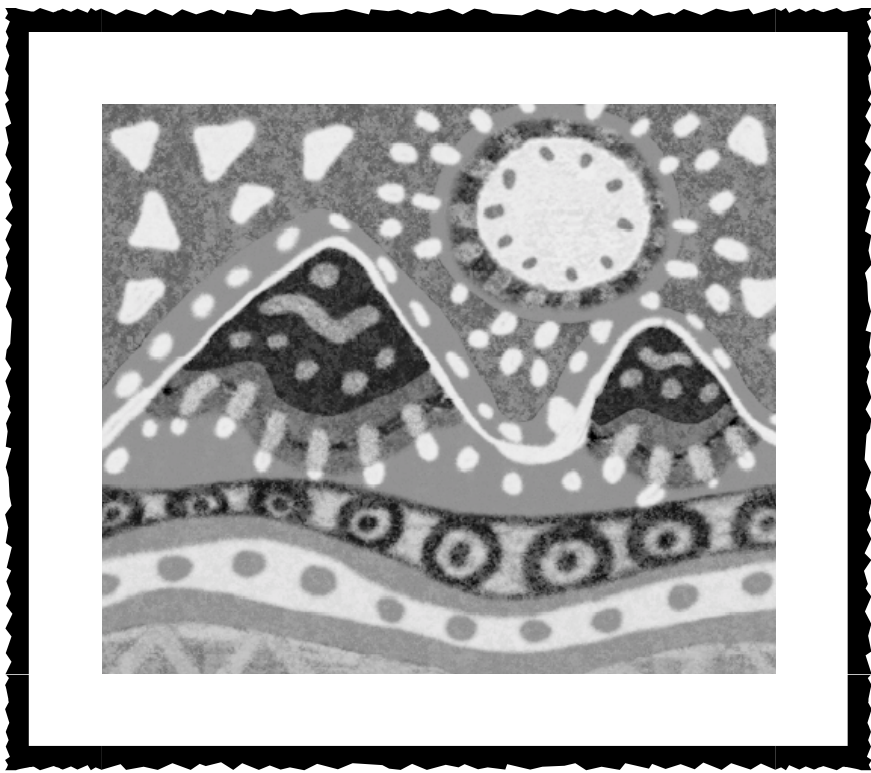
Other than Australia, New Zealand, and the UK countries, no other countries appear to be collecting national data on young caregivers or developing large-scale programs, despite the apparent need.

Next Steps

According to the National Alliance for Caregiving, a number of actions will be taken as a result of the international conference. The international caregiving listserv has been expanded to include all conference participants. In addition, NAC has developed a matrix on international caregiving government policies, which is available on its Web site (www.caregiving.org).

Most importantly, NAC hopes that conference participants will be able to use the valuable lessons learned from other countries to forward caregiving improvements in their own. The Fourth International Conference on Family Care will be held in 2005 at a location to be determined in western Europe.





Appendix

The following experts reviewed the sections of the International Comparison listed below:

U.K. — Diana Whitworth, chief executive, Carers UK, London

Australia — Warwick Bruen, Assistant Secretary, Community Care, Department of Health and Ageing, Canberra

Sweden — Lennarth Johansson Ph.D., Research Leader, National Board of Health and Welfare, Stockholm

United States — Rick Greene, Program Specialist, The National Family Caregiver Support Program, Administration on Aging, DHHS, Washington, D.C.

Israel — Israel Doron, Faculty of Health and Social Welfare, Haifa University, Haifa

Canada — Bonnie Schroeder, Canadian Caregiver Coalition, Secretariat

Supporting Documents Used for International Comparison of Caregiver Policies

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Swedish Health Care Structure Paper by Kevin C.L. (student) available at <http://hadm.sph.sc.edu/Students/KCLNet/swedpapr.htm>

Centrelink, Income and Assets Tests for Carer Payment, Australian Government and available at http://www.centrelink.gov.au/internet/internet.nsf/payments/carers_jat.htm

International Currency Exchange Calculator at <http://www.x-rates.com/calculator.html>

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