

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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Introduction

On October 12-14, 2002, nearly 700 caregiving advocates and policy makers from 22 nations met near Washington, D.C., 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 underappreciated 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 U.K. 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.” The terms are used interchangeably in this report.

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 U.K. 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 long-term care, personal care, or outpatient prescription drugs. Nursing home care is available

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.

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 workforce 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 argu-

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

ment that helping caregivers is an indirect way of ensuring that the elderly are properly cared 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 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

Carer advocates need to lobby their cause better.

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 US, 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

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

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 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 ac-



tivities 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.



Developing Successful Caregiver Support Programs: Three Perspectives

At a dinner during the conference, the Alliance presented Caregiving Best Practice Awards to three organizations for their exemplary work in developing and operating support programs for family caregivers. Each award winner was invited to write a “how to” guide offering insight into what it takes to create and operate a successful program.

What follows are the results of the award winners’ efforts. We hope that anyone who is thinking of beginning a caregiver support program will find these guides useful. We believe you will find these guides to be filled with pragmatic advice that can be applied in nearly every community.

2002 Caregiving Best Practice Award Winners

Carers NSW (Australia)

CLSC René-Cassin (Canada)

Family Caregiver Alliance (United States)

How to Develop and Conduct Successful Support Programs for Family Carers

Carers NSW, Australia

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Terminology

Carer: This term is used in Australia to describe relatives and friends who are caring for people with a disability, mental illness, chronic condition or who are frail aged.

CALDB: Culturally and linguistically diverse backgrounds—people who come from a range of different countries and cultures.

Koori: Aboriginal people in southeastern parts of Australia.

Yarning: Talking and listening to stories.

Young Carer: This term is used in Australia to describe children and adolescents under 18 years who have caring responsibilities for people as described in the definition for carer.

Background

Carers NSW is the peak body in the State of New South Wales (the most populated State of Australia), which represents relatives and friends who are caring for people with a disability, mental illness, chronic condition or who are frail aged. Our organisation began in 1976 by a remarkable woman, Clare Grant Stevenson. After the start of World War II Clare was selected to head the Women's Auxiliary Australian Air Force. This position made her the most senior officer of the four women's services within the Australian Defence Force.

At war's end and upon completion of further studies, Clare collaborated on a report "Widows in Australia" published in 1963. The result of this report was a complete change of policy by the Federal Government toward civilian widows. Later she organised a scheme to give scholarships to the children of civilian widows.

During International Women's Year 1974, the Council on the Ageing was given a grant to find out the extent of care given by family and friends to the frail aged and, as they were then referred to, the handicapped. As Research Officer with the Council, Clare was responsible for the report on a survey of some 427 people who were caring at home in Sydney.

The report was published under the title "Dedication." That title not only characterised the people of the study, but also Clare's approach to her work and her consequent activity in the cause of carers. Clare established a sub-committee under The Council on the Ageing with a group of dedicated volunteers working for the recognition of the needs of these people and the first step was to give them an identity—she called them 'the Carers'.

The Carers Association of New South Wales (renamed Carers NSW Inc in 1997) became an independent body in 1980 with Clare as Founder President, and with the same band of willing volunteers. In 1981, Carers NSW became a registered charity.

1985 saw the culmination of Clare's many years of lobbying Governments when the Carers Pension became available to some thousands who had devoted their lives to caring for friends and loved ones in their own homes. This was also the year the State and Federal Governments' of Australia jointly funded Home and Community Care Program.

Carers NSW is now in its strongest position ever to represent New South Wales carers and to provide accurate and appropriate information and advice to carers. It carries out community development work, runs education programs about carers, researches carer issues and develops and pilots support options or programs for carers. In particular, development work in indigenous and culturally and linguistically diverse communities has increased during the last few years.

Funding

Carers NSW received its first grant of \$A37,000 from the government in 1987. Currently, it receives government grants from both State and Federal Governments, as well as income from member fees, donations and services and resources provided by Carers NSW. The income for 2001/2002 is in excess of \$A2,160,000.

Demographic Characteristics

The carers we represent are spread across a huge area. To give you an idea of the size of New South Wales, it takes approximately 25 hours to drive along the coast from its southernmost point to its northernmost point (the state is narrower on its inland side). It takes about 20 hours to drive from Sydney, the capital city of New South Wales, on the coast, directly west to its most inland point. New South Wales contains three relatively large metropolitan areas (Sydney, Newcastle and Wollongong), hundreds of medium and small size towns and many tiny towns. There are also vast tracts of open space. While most of the population is concentrated in the three largest cities, there is a huge geographic spread of people in rural and remote areas. The carers we represent have the characteristics described in Table 1.

Number:	798,300, of which 162,200 are primary carers (1998)
Age:	75% of carers are of workforce age (i.e. between 18 and 65 years).
Employment:	48% of carers are employed, with a further 6% looking for paid work.
Income:	Carers' Association of Australia research in 1997 -98 found that 69% of respondents had incomes of \$A299 per week or less.
Indigenous:	12% of our indigenous population is believed to have caring responsibilities. This equates to at least 14,500 carers.
Cultural:	25% of the total population is from CALDBs.
Diversity:	CALDB communities are thought to have a higher incidence of caring than Anglo-Australian communities.
Urban/Rural:	Approximately 80% of the NSW population lives in one of the three major metropolitan areas, with the remainder in large or small towns.
Young Carers:	There are at least 54,000 carers aged under 18 in NSW.

Table 1 Selected demographic characteristics of New South Wales's population.

New South Wales has the largest population from non-English speaking backgrounds of any state in Australia and also has a relatively large indigenous population. Most of the carers from culturally diverse backgrounds live in Sydney, whereas the majority of indigenous carers reside in rural and remote areas.

Overview of Carers NSW Support Programs

Carers NSW runs a number of carer support programs, some of which are linked. Innovative programs include:

- Telegroup counselling (Talk-Link) *
- Koori Yarning Project *
- Young Carer Project *
- Connections Project—linking parents of children and adults with developmental disabilities
- IT Support like E-support groups, chat rooms
- CIRC (Carers Inclusion in Residential Care)—a training program for staff and management in aged care facilities.

*These projects were profiled for our International Caregiving Award Nomination.

Characteristics

The unique characteristics of our programs include the following:

- **Non face-to-face delivery**
The use of technology, in particular information technology, permits us to overcome the tyranny of distance, given that we have to service such a geographically spread clientele. Car-

ers can be provided with service in the comfort of their own home, in the case of telegroup counseling, internet support groups, and email groups. This also overcomes the problem of accessing respite which, although available, is insufficient to meet all of the demand.

- **Regional service development**

While the Carers NSW office is based in Sydney and we speak to carers from across NSW on the telephone, we often take our service to local communities and assist to develop the skills and knowledge to conduct the programs on an ongoing basis. This results in pilot projects becoming sustainable and provides better equity of access across New South Wales.

- **Programs targeted at specific groups of carers**

The programs were developed with the needs of the target groups in mind, which may have necessitated non-standard approaches. For example, respite services for adult carers are not appropriate for young carers. Therefore a completely different approach is taken with young carers. The Koori Yarning project takes into account the particular needs of the indigenous community. Carers NSW has always developed different tools for addressing the first stage of service delivery, i.e., assessment. Known as the Carer Profile, it provides service providers with an understanding of carer needs and a tool for including those needs and issues when during assessments. This has been adapted for specific groups of carers.

- **Use of appropriate facilities**

Given the special needs of particular groups of carers, as outlined in the previous point, our programs had to be delivered in appropriate surroundings. We had to procure camp sites for young carer camps and Aboriginal venues, where possible, for the Koori Yarning project. This sometimes necessitates partnerships with other organisations. The Federal Government has recently funded Community Technology Centres, which helps address some of the access issues for people who do not have their own computers for our IT programs.

Elements of a Successful Program

How the Projects Get Started

A key element of developing a new program is a sound knowledge of the sector you are working in. This includes not only the carers, but the service sector as well. If working in regional areas, differences between areas must be taken into account. Sound knowledge may be developed through doing community development work in an area, through good relationships with carers and services in a locality, or may arise from research that has been conducted. This, in turn, may lead to the identification of unmet needs or even new needs. Having workers dedicated to specific groups of carers means that workers can focus on the group's particular needs.

Methodology for Developing a Successful Project

We have found that the following process helps us to develop a project that runs smoothly and avoids most problems. This process involves:

- **A thorough planning stage**

As indicated in the previous point, our planning is based on a sound knowledge of the sector, of the needs of carers and usually on the efforts of workers dedicated to working with particular groups of carers or in particular sectors. Planning involves determining who you are targeting and why, how best to do it, what you hope to achieve, how you will promote the project, how it will be evaluated, the resources required, possible funding sources, strategies for sustainability and how you will publicise the results. Planning also allows con-

sideration of how the project will impact upon the organisation and inform its other work.

All planning is documented, draws on relevant research and is set in the context of other initiatives within the sector.

- **Consultation with other organisations**

Consultation is conducted for two main reasons. The first of these is to assist with planning the project. Consultation with both carers and service providers allows you to ascertain the needs that exist, especially in different local communities and in different carer populations.

Second, consultation permits you to find out whether any other organisations are doing similar work. If you do not research this first, you may end up replicating their efforts or wasting time 'reinventing the wheel'.

Consultation also aids in building the relationships which are so important to the implementation and sustainability of the project.

- **Management of the Project**

Generally speaking, one key worker will have overall responsibility for the project. However, there will also usually be other accountability mechanisms in place, such as reporting to a Board of Management and/or to funding bodies. It is often useful to set up an Advisory Committee to guide the Project Officer and to provide expert advice. This committee can be made up of key organisations within the sector, a representative of the funding body, carers and perhaps other staff within your organisation. Such a committee provides a forum for a broader spectrum of ideas to be canvassed.

- **Evaluation**

Evaluation must be seen as an integral part of any program. Ideally there should be some internal evaluation by your organisation, but also an independent evaluation, if resources permit. By incorporating evaluation into the planning process, mechanisms can be put in place to ensure that the data you require for meaningful evaluation can be obtained during the course of the program.

Political/Financial Strategies

On the political front, good relationships with all levels of government, service providers and media are essential. Not only does this result in the organisation being well respected and perceived as capable of carrying out the project, it also means that funding is more easily procured. Organisations that provide submissions based on respected and recent research will be better placed to be successful.

When seeking funding it is important to keep abreast of all the different financial opportunities available and to sometimes be creative with how a project is funded. For example, our Koori Yarning project was funded by a combination of grants from different government departments. The downside of this, of course, is that adequate financial reporting mechanisms must be in place and your financial system must enable you to keep on top of what money comes from where and goes where.

Also make sure you factor in a management fee of 25% -35% to be used for administrative, financial, IT and overall management of projects.

Barriers Overcome

Through the use of IT and telecommunication, we have been able to overcome barriers associated with distance and isolation. One of our challenges is to be able to work with a diverse range of organisations, both government and non-government. These include organisations and government departments representing the aged sector, disability sector, mental health sector, and the health sector.

Even though the relationship develops through representation on a variety of committees and working parties, the best result has been when the sectors come together to work on a particular project. This process allows for trust and partnerships to develop. In Australia, governments are encouraging the formation of consortia that bring together a small or large number (3-6) of organisations working together on a particular project. Often these will be pilot projects, which, through evaluation, can often form evidence for ongoing services.

Keys to Success

First and foremost, we believe that we succeed because of our good knowledge of carers' needs. The programs you develop must be relevant to carers' situations. It is no use offering something that no one wants. This we achieve by direct contact with carers through our support and information telephone service, as well as our research and pilot programs.

Second, our reputation as a dynamic organisation means that we can procure funding where others might not and that other organisations are willing to work with us. Our reputation has been gained, we believe, partly through ability to work constructively with government and other organisations, partly because our projects are based on sound knowledge and partly through our willingness to try new approaches (see also point below).

Third, our willingness to tackle the new and difficult has helped us succeed. Good planning processes, as outlined above, should help minimise difficulties, even when testing new approaches or working in areas that you have not worked in before. Linked with the previous point, a willingness to innovate also leads to a reputation as a dynamic organisation.

Fourth, the ability to realistically assess limitations and put in place strategies to overcome them has assisted. For example, in many areas of NSW carers have limited access to respite care. Therefore it may be difficult for them to get out of the home. However this has not stopped us from working with these carers. We have used technology to bring services into people's homes and have developed programs to build the skills of carers so that they can advocate for improved services in their local area.

Measuring Success

As mentioned in the Methodology section, evaluation needs to be built into a project from the planning stage. Evaluation, naturally, will incorporate an assessment of whether the project's aims and objectives (i.e., outcomes) were achieved. However, to fully inform ongoing projects, or other projects you might conduct, it should also include evaluation of the processes undertaken in conducting the project. Therefore, evaluation should also include a number of other measures. These might include:

- the number of referrals received and whether this was adequate;
- sources of referrals—did this increase?;
- number of enquiries about the project—from both carers and service providers;
- an assessment of whether networks were built;
- the ability to identify local issues and report these to the appropriate places; and
- whether carers or workers learned skills.

This feedback can be obtained from carers, service providers, staff of the project, partner organisations, volunteers, representatives of the local community or anyone else who could usefully give input. Your evaluation will only be limited by resources and what can realistically be achieved with them in the time frame available. The evidence helps to develop pilot programs into ongoing carer support programs.

Outreach Strategies for Carers

In general terms, there are a few key ways in which we reach out to carers. These are:

- **Legwork**—if necessary many phone calls and large mailouts are conducted. We use our existing databases—such as carers who call our information line and our membership database.
- **Through partnerships**—we are well-linked with the network of 17 Carer Respite Centres across the state and also have contacts with many other organisations. They can assist us in recruiting carers to participate in programs.
- **Advertising**—in our monthly newsletter, in other organisations' newsletters (if possible) and by obtaining media coverage in local newspapers or on local radio.
- **Through community development work**—by giving information/education sessions to various key services, those services become an important source on ongoing referrals to our programs. This necessitates follow-ups at regular intervals.
- **Media strategies**—we employ a media strategist to monitor press stories and develop relevant media releases.


Community Coalition Building

Carers NSW facilitates a statewide Carers Coalition group who identify a project or issue that is relevant for its members and their organisations. The outcome is an effective collaboration and usually a joint campaign or position paper on a carer or related issue identified by the group. All our innovative projects have advisory committees and usually operate using a consortium. We also facilitate a Multicultural Carers Alliance and are in the process of developing an Indigenous Advisory Group. These form an easily accessible model or framework for partnerships and collaboration.

Lessons Learned

There are five main areas in which important lessons have been learned. These lessons have informed the way that we will develop new programs in the future.

The first of these lessons is to be careful to cost the project properly. This means taking into account the true costs of all the development work within the organisation, the staff time that this involves and allowing enough time within the project to get it up and running. With new projects,



this can involve intensive work in the field in the initial stages as promotion is conducted and time spent building relationships with organisations that can refer on to your program. Other costs which need to be included are: travel, promotional materials, administrative and IT overheads, equipment, printing, publicity of the results (e.g., attendance at conferences and seminars) and respite for carers (if necessary). As mentioned previously, factor in a 25% -35% management fee. Needless to say, if the project is not costed properly, your organisation can end up subsidising the project out of its own funds.

The second main lesson we learned was that when working with particular groups of carers, the timing of stages of the project may vary. For example, some indigenous communities have a different culture around time. If you expect the project to proceed as it would with mainstream communities, you may experience frustration at the perceived 'delays'. In other words, be creative and flexible and adjust timeframes to suit different groups of carers. It is important to have effective planning and timeframes, but rigidity is not useful with carer support programs.

The third lesson, related to the first above, was that where you are providing emotional support or counselling to carers, you must factor in support/debriefing time for the staff providing the service to carers. Retreats, in particular, can be emotionally very intense in a short space of time. Have back-up staff available with their hours costed into the project so that adequate support is available to project staff. This may also include clinical supervision when necessary.

The fourth lesson was around working in partnership with other organisations. While partnerships can be immensely beneficial, they also involve quite an investment of time and energy to make them work. Each organisation will have its own aims, goals and agendas. One organisation will probably need to take a lead or coordinating role in the project. Training for one or all of the organisations may need to occur. Again, this should be factored in to the costing of the project so that the project costings reflect the true amount of effort involved. It is also important to keep the funder involved throughout the project through reports and participation in advisory committees or meetings.

The fifth, and final, main lesson was about the sustainability of projects. When working with a new initiative in an area that has substantial unmet need, certain expectations are created, as well as excitement and enthusiasm. Hopefully your project will harness this energy and put it to good use. However, it is important to consider what happens at the end of the project, when funds have run out. It can sometimes be a source of grave disappointment to carers and participants when the project team withdraws and the program stops. Therefore, we have learned the importance of considering and building into our projects, where possible, strategies to make them sustainable. The results of the evaluation of the project, as mentioned earlier, will naturally inform how the project continues in the future.

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The CAREGIVER SUPPORT CENTRE of the CLSC René-Cassin/Institute of Social Gerontology of Quebec (ISGQ)

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Overview

Context and Clientele Served

Within the province of Quebec, CLSCs (Local Community Service Centres) play a vital role in the health and social service sector serving as the primary portal for individuals of all ages requiring health and social service assistance. Utilizing a global, multidisciplinary and community approach, CLSCs have established a mandate intended to provide the optimal quality of care for individuals within their communities. Equally important to their mission is the emphasis on individual responsibility with respect to the maintenance of personal well being. Through CLSCs, individuals are given access to services and programs that offer curative treatment as well as preventative strategies. There are 147 CLSCs throughout Quebec all funded by the provincial government, each responsible for providing services to different sectors of the province.

The CLSC René-Cassin/ISGQ is a public health and social service establishment and is an affiliated University Centre, working jointly with three Montreal based Universities (McGill University, University of Montreal, and University of Quebec at Montreal). The CLSC René -Cassin/ISGQ serves a population of 47,000 people in the greater Montreal area.

At 27.1%, the CLSC René-Cassin/ISGQ has the highest proportion of residents aged 65+, as compared with Montreal (14.9%) and the rest of Canada (12.5%), and with the USA (12.4%). This characteristic has prompted the development of innovative services and research activities in social gerontology in order to better serve the seniors in our territory. In the CLSC René -Cassin/ISGQ territory, many elderly individuals in the area live alone (36.9%) in stark comparison to the 16.3% of the general Canadian population who live alone (Statistics Canada, 1996). The majority of the 65+ population within this territory are women. The CLSC René -Cassin/ISGQ territory is predominantly Anglophone (68.8%). Nearly 41% of the residences are immigrants to Canada with countries of origin including Poland, Morocco, Romania and the former Soviet Union.



The Caregiver Support Centre Historical Review

The Caregiver Support Centre of the CLSC René -Cassin/ISGQ was initiated on February 16, 1993 and has evolved over the past nine years into a thriving multi -faceted program offering a full range of services to caregivers. At the time, the only service available was a "Drop -In Centre", which provided occasional or emergency respite to caregivers by organizing stimulation activities (social, motor and cognitive) for care -receivers.

Less than one year following the introduction of the "Drop -In Centre", the program was evaluated by a consultation team composed of several CLSC professionals and external partners. Through the experience gained over the course of the previous year, and through ongoing interactions with the caregivers themselves, it became evident that occasional respite was insufficient and that caregivers needed additional support. The outgrowth of that evaluation process is the current Caregiver Support Centre that was officially inaugurated in January 1996.

In response to the growing and specific needs of caregivers, the CLSC René -Cassin/ISGQ developed the Caregiver Support Centre to address critical caregiving issues presently arising within our health care system. The Caregiver Support Centre is an innovative, multi -faceted service program for caregivers developed at the heart of the community. The Centre responds to the growing and diverse needs of caregivers and multidisciplinary professionals working with and on behalf of caregivers. The Centre is focused on maintaining and enhancing the well-being of caregivers through outreach and prevention, support, education, information, advocacy, and empowerment. It serves to promote and identify research related to practice in partnership with professionals and community organizations. The Centre provides training to professionals through conferences, training packages and workshops while maintaining strong links to universities and an ongoing internship program for undergraduate and graduate students. As well, the Centre has an ongoing contact with the community and a vibrant group of volunteers who have a fundamental role in the Centre and its programs.

An in-house study concluded that 95% of Caregiver Support Centre participants and caregivers require more social service assistants than the Centre can offer. In order to make room for this demand, clients who have already been integrated into the service network of the Caregiver Support Centre are often referred to another service attached to the 60+ department. The 60+ department includes Home Care, Mental Health, Elder Abuse and Well-Aging programs, as well as the Caregiver Support Centre. Conversely, case managers in the various departments refer their clients/caregivers, when appropriate, to the Caregiver Support Centre. Since the services are all under one roof, this maximizes the concept of an integrated and interdisciplinary service model. Caregiving clients receive a full case management approach to their unique needs.

Description of the Centre's Programs

The Caregiver Support Centre serves to promote the autonomy, well-being and quality of life of caregivers. Services provided for care -receivers are intended to combat isolation, enhance socialization and renew the caregiver/care -receiver dynamic. Direct services available to caregivers and their care-receivers include:

- **The Drop-In Program:** provides caregivers with respite by organizing activities for care -receivers who have a physical and/or cognitive impairment or mental health issue. Seniors suffering from a loss of autonomy who would otherwise remain isolated in their homes benefit from group activities that are tailored to their individual needs. These activities are conducted by trained staff, students, and volunteers. Flexibility of Drop -In hours allows caregivers to bring their care-receivers when it is convenient for them (15 -25 participants/day).

- **The In-Home Stimulation Program:** available to seniors or disabled adults who are isolated, frail and confined to their homes. Volunteers and students, trained and supervised by a professional, offer a variety of in-home stimulation activities on a one-to-one basis. Activities are tailor-made to individual interests and levels of functioning. During periods of engaged stimulation between students/volunteers and the care-receiver, caregivers are afforded respite each week for 2-3 hours (80-100 caregivers and participants/year).

Another aspect of the In-Home Stimulation program is the In-Home Stimulation Program Building Project, a group stimulation program organized for residents in buildings that are highly populated by seniors in the CLSC René -Cassin/ISGQ territory. The seniors in each building are frail and especially isolated during the winter months. The groups focus on enhancing individual socialization, promoting neighbourly contact (buddy systems) and encouraging stimulating activities. These activities are organized by trained volunteers (3 buildings, 25 participants/building).

- **The Foyer Program:** offers caregivers information, education and support from professionals and trained volunteers who are themselves caregivers. Caregivers can take part in daily or weekly programs, such as support groups, workshops, and have access to a documentation centre with information on disease, coping strategies and resources. Outreach to the professional and public communities is conducted through foyer activities, which include marketing and promotional strategies intended to broaden social awareness surrounding caregiver issues. Additional programs, such as conferences and advocacy activities are also planned to promote the rights of caregivers (170 caregiver visits/year).
- **The Short-Term Counseling Program:** provides an 8-10 week counselling program for caregivers with a focus on coping skills, stress mediation, limit setting and linkage with respite/support programs. The program is staffed by a professional social worker trained in caregiving issues. In addition to the implementation of therapeutic models of intervention, the social worker is responsible for evaluating caregivers, assessing individual needs for services and making appropriate referrals to other services (80 caregivers/year).
- **The Caregiver Info Line:** provides caregivers and community members with access to information on services and programs offered by the Centre. In addition, the telephone line is available to professionals, the general population and other related organizations requiring information on caregivers (40 calls/week). The number is (514) 485.7374.
- **The Caregiver Advisory Committee:** a council made up of 15 volunteers, all of whom are or have previously been caregivers. The Advisory Committee members are dedicated to promoting the rights of caregivers and pursuing their interests within the Caregiver Support Centre. Many valuable and effective programs have been developed within the Centre as a result of ideas that were initiated by members of the Advisory Committee. In addition to the work conducted within the Centre, the committee has gone on to develop its own autonomous grassroots organization called Project O.A.S.I.S. (Outreach, Advocacy, Support, Information and Sensitization). Project O.A.S.I.S. is a non-profit, local community group comprised of volunteer caregivers dedicated to enhancing the quality of life of caregivers. This includes increasing individual and public awareness through ongoing education, information and advocacy plans.
- **Student Training Programs:** conducted jointly with Montreal universities and colleges. The Field Placement Program of the CLSC René -Cassin/ISGQ recruits students and provides them with a comprehensive internship program through which they gain invaluable first hand experience in their field related to the elderly population. The training program focuses on caregiving issues, issues related to aging, cognitive and physical impairments, special needs, etc. Special seminars are also organized to ensure that students receive information on a wide array of topics related to caregivers. Evaluative tools are employed in

order to determine student's attitudes towards the elderly prior to and following their field placement. These qualitative measures provide the CLSC René -Cassin/ISGQ with invaluable feedback and reveal the impact of CLSC René -Cassin/ISGQ professional practice on students' perceptions of the elderly.

- **Volunteer Training Programs:** vital to the inclusion of community partners within a professional practice setting. Since its inception, the Caregiver Support Centre has relied heavily on the talent and dedication of its many volunteers. These individuals are needed on a daily basis to work within various programs in the Centre. Formal and informal training sessions are offered to volunteers. Supervision is viewed as part of the entire training process and the staff at the Caregiver Support Centre provide frequent feedback to the volunteers regarding their interaction with the caregivers and care-receivers.

Innovation

The Caregiver Support Centre of the CLSC René -Cassin/ISGQ is unique to Québec. Over many years, we have developed an integrated Centre that is constantly evolving to address the needs of its caregivers. We have come to understand that our work on behalf of caregivers is a work in progress, evolving and challenging, much like the realities of caregiving. We strive for equality, responsive services and we continue to apply for grants and funding for research projects that can help to examine and better the lives of caregivers and care-receivers. The rights of caregivers in our society will remain the primary focus of our work in the Caregiver Support Centre. We place a high value on the work conducted by volunteers within the Centre and make efforts to outreach to the community wherever possible. The innovative tenets that guide our work include the following:

- A service that relies heavily on caregiver feedback (through Advisory Committees and community involvement) in order to develop services and programs. Community involvement has been an essential component for addressing caregiver needs.
- A service that is flexible, non-bureaucratic, and provides facilitated access.
- A service that is cost-effective through the participation of volunteers and students who provide most of the direct services in the Centre.
- A service that responds directly to caregivers' needs for respite, while providing the care-receivers with stimulating activities.
- A service that offers support, information and education, while empowering caregivers through conferences, support and self-help groups.
- A service that responds to isolated seniors, bound to their homes.
- A service that has become reputable and sought out as a training ground for students of universities and colleges in the fields of social work, nursing, occupational therapy, physiotherapy, medicine, special care counselling, etc.
- A service that is recognized by the health care community as a centre of expertise regarding training on caregiving issues and needs.
- A service that is constantly involved in identifying the needs of caregivers through involvement in research projects in partnership with the community and other resources.

Description of the Caregiver Support Centre

Background and Methodology

Within the CLSC René-Cassin/ISGQ, the Caregiver Support Centre is designated a 'cutting-edge' service. A 'cutting-edge' service is a program in which a model of intervention is developed based on a demonstrated need. The determination of need is identified based on external

and internal determinants and include issues raised from clients, practitioners, from orientations of the Quebec Ministry of Health and the Regional Health Board, and from findings in research. The innovative model of practice developed to respond to this need, by definition, must be global in vision, multidisciplinary, innovative, must improve practice and service delivery, provide expertise in a specific domain, and this expertise must be transferable. Specifically, in order to be considered a 'cutting-edge' service, the model of practice must consist of four inter-related components: 1) Direct Services; 2) Partnership; 3) Research; and 4) Transference of knowledge. Other 'cutting-edge' services within the CLSC René-Cassin/ISGQ include the Community Mental Health Program for Older Adults, the Elder Abuse Consultation Centre as well as the Well-Aging Program. There are three complementary stages when developing a 'cutting-edge' service:

1. Identification of Need

A gap in services for the community is identified but there have not been any specific activities developed in order to respond to this need. Professionals within the CLSC begin the inquiry process (meetings, committees, focus groups, etc.) in order to lay the groundwork for a potential service model. Existing models of practice are identified and data collection begins on the proposed area of interest (literature review, brainstorming, attending conferences, feedback from external service providers, etc.).

Example: Case managers report a high incidence of psychosocial distress and an absence of resources and support services for their clients. The CLSC René-Cassin/ISGQ gathers together a group of professionals from different disciplines to discuss the issue of caregiver needs within the territory.

2. Review of Need and Research

At this second stage, there are several indicators that the identified area seems to respond to a specific community need. Work done in the previous stage is refined. The decision is taken in order to better identify the need which includes the development of a hypothetical practice model through pilot projects, the training and sensitisation of staff, the integration of information collected from research activities and ongoing input from the health care network. Researchers and service providers are more deeply implicated in the development of a refined practice model through the combination of theory and practice.

Example: The broad outlines for the Caregiver Support Centre are developed based on research activities and feedback from professional partners and clients. Preliminary respite services are developed as a pilot project (i.e. Drop-In Centre). CLSC René-Cassin/ISGQ staff are provided with training modules on caregiver issues.

3. Development of a Practice Model

A service becomes a 'cutting-edge' service when certain internal and external components are combined. Practitioners within the CLSC René-Cassin are trained and encouraged to develop an expertise on the issues relating to the program model. Concerns by stakeholders (older adults, practitioners, researchers and policy makers) are identified and integrated into the practice model. The program model is executed and continually evaluated. Findings are presented at conferences and submitted as articles in journals and relevant publications. Ongoing adaptations are executed through re-evaluations and input from health care partners.

Example: The Caregiver Support Centre is established to address caregiver needs. Professional committees centred on caregiving issues are founded to serve as a hub for new ideas and potential adaptations to existing models and standards. The Centre conducts research

to evaluate its services and publishes those results for professionals and the public.

Political/Financial Strategies that Worked

Political

- The CLSC René-Cassin/ISGQ is mandated by the Québec government to address community health and social service needs, and as such was driven by its own social agenda.
- Inter-departmental recognition within the CLSC René -Cassin/ISGQ of the necessity of creating services for caregivers within the community, and the innovative solutions proposed by the program model of the Caregiver Support Centre, was a sufficient impetus for the development of the Centre.

Financial

- The partnership between the CLSC René -Cassin/ISGQ and Montreal-based universities has facilitated the creation of an internship program for students who are being educated in the disciplines of social work, nursing, gerontology and other health related fields of study. Under professional supervision, they assume a central responsibility in the delivery of services and adaptive programming, thus reducing program costs.
- Volunteers (many of whom are or have been caregivers) play a vital role in the Caregiver Support Centre, offering their commitment and expertise through hands -on work with caregivers and program development.
- Drop-In participants provide a small financial contribution (Can\$7 -\$12) on a sliding scale (no one is refused for financial reasons) in order to supplement transportation and supplies.

Barriers Overcome

- Creating an accessible, safe and stimulating environment was a challenge at the outset of the project given that the Centre was created within a professional office setting. The Drop -In Centre and the Foyer for caregivers required a great deal of physical space in order to accommodate the number of caregivers participating in group activities. Integrating an ambient, interactive and relaxed space within the existing professional framework required special care and consideration both for our clients and our colleagues.
- Numerous seniors within the territory lacked sufficient means of transportation due to losses of autonomy and debilitating physical and cognitive illnesses. Developing a transportation system that enabled care-receivers to be delivered to the Caregiver Support Centre overcame this frequently encountered problem. The In -Home Stimulation program, created in part to address the needs of isolated and frail seniors, also responds to this barrier by engaging clients in activity programs through home visits.
- The diversity of client needs (spectrum of physical and cognitive disabilities) meant that the activities of the Centre would need to be very flexible as well as adaptable to individual interests and levels of functioning.
- At the outset, many caregivers arriving at the Caregiver Support Centre were already in the throes of crisis, experiencing progressed emotional and physical symptoms. The Centre has devoted considerable efforts, through sensitization and marketing devices, to effectuating preventative care strategies. Assisting caregivers before the onset of debilitating stress and burden is a central concern in the Caregiver Support Centre.

- Many individuals providing care do not identify themselves as 'caregivers'. Others have difficulty accepting help and support. Defining their role, discussing their rights and liberties and the availability of resources have assisted caregivers in reducing feelings of isolation and excessive burden, helped them to examine their responsibilities as care-providers and encouraged them to engage appropriate measures of support.

Keys to Success

- The creation of an Advisory Committee made up entirely of caregivers provides the Centre with a direct link to the population it seeks to assist. The committee serves an integral role in the process of decision-making and program development and has assisted greatly in the creation of effective and focused services.
- Developing links to professional consultative committees has provided the Caregiver Support Centre with an invaluable network of support, information sharing and innovative orientations for future projects. An example of a group initiated by the Caregiver Support Centre is the Professionals Networking for Caregivers (PNC). The PNC is a local group with representation from over 22 health care facilities throughout the Montreal area. The mandate for this committee includes looking at the continuum of care, the needs of caregivers, and sensitization to professionals in the community. Other professional partnerships include Project O.A.S.I.S. as well as the Canadian Caregiver Coalition (CCC). The CCC is a bilingual alliance composed of organizations, groups and individuals. The mission of the Canadian Coalition for Caregivers is to come together with a unified voice, to influence policy, and to promote awareness and action to address the needs of informal caregivers of all ages across Canada (www.ccc-ccan.ca).
- The utilization of media services helped to promote the Caregiver Support Centre during its inception and provided a marketing platform to caregivers in the community.
- Given the degree of burden and stress experienced by caregivers in difficult circumstances, the Caregiver Support Centre insisted on developing a non-bureaucratic approach to facilitate an easy entry process for caregivers requiring immediate assistance and support.
- The idea for the Caregiver Support Centre was inspired by feedback from front-line workers and clients. Direct feedback was pivotal in creating a Centre that addressed expressed needs rather than hypothetical ones.
- Partnership with professional organizations as well as university affiliations has promoted the creation of a health service network whose ongoing input and collaborative work has allowed for the creation of an effective service delivery program that is rooted in professional practice as well as research.
- Marketing campaigns to caregivers in the community has assisted the Centre in exposing the issues affecting caregivers' lives, as well as promoting the rights of caregivers, and the availability of resources (services, conferences, programs, workshops, etc.).

Evaluation

- In May 1998, a research team composed of health care professionals conducted research on the Utilization of Services in the Caregiver Support Centre (Lessard, Diane; Barylak, Lucy; Côté, Dominique; Bérubé, Louise, May 1998 to October 1999). Information gathered from this research provided the Centre with qualitative feedback in order to measure the effectiveness of services as well as the need for adaptations.

- Questionnaires given to our caregiving clients provide us with ongoing feedback as to the impact of Caregiver Support Centre services and activities on caregivers lives (reductions in stress, enhanced knowledge, improvement in care-receiver/caregiver dynamic, etc.). This needs assessment campaign is an ongoing strategy employed by the Centre to create adaptive, flexible and responsive services.
- Feedback from Case Managers provides Caregiver Support Centre social workers with an immediate assessment of the status of clients and the impact of specific services on their overall functioning. Case Managers provide the Centre's workers with a broad vision that includes the how and why, and under which circumstances particular services provide greater assistance than others.
- Professional consultative committees and the Caregiver Advisory Committee assume a central evaluative function. Their expertise provides an environment in which services and programs can be evaluated, jointly discussed and comparatively measured.

Outreach

The Caregiver Support Centre encourages caregivers to utilize available services and to maximize community resources. All outreach services within the Centre are organized to meet the education and support needs of the community. In order to connect with and respond to the needs of caregivers in our community, the Centre is engaged in the following outreach activities:

- **The Caregiver Support Centre Annual Conference**—This conference is developed and organized in conjunction with the Caregiver Advisory Committee. The conference is open to the general public as well as to all health care professionals. The 2002 conference will address the issue of "Wills and Mandates". The 2001 conference focused on how to access services in the health care system.
- **Bi-Annual Caregiver Celebrations**—Every year the Caregiver Support Centre hosts a "Day in the Park" during the summer as well as a Holiday Party in December. The gatherings are open to caregivers and their care-receivers and are intended to create a festive atmosphere in which caregivers can socialize with peers and health care professionals in an informal context. It is also an opportunity for caregivers and seniors new to the Centre to meet others and discuss some of the available programs.
- **Information Kiosks**—A portable marketing kiosk has been developed in order to promote the Centre's services. These booths are staffed by health care workers, students and volunteers who distribute pamphlets and information in public areas that are frequented largely by seniors and families.
- **Flyers and Newspaper Articles**—A marketing strategy has been established that allows for an ongoing flyer distribution campaign as well as the publication of articles in Montreal based newspapers and community calendars regarding the Caregiver Support Centre's services and programs.
- **Outreach to Diverse Community Groups**—Outreach materials have been developed specifically for presentations made to different communities in order to discuss issues related to well-aging and caregiving.
- **Support, Information and Psychosocial Groups**—Caregiver support groups comprise the therapeutic dimension of the Centre's outreach practice. Caregivers benefit from a safe, inclusive and open environment. These groups offer a place where caregivers can meet with others in similar situations to exchange, problem-solve and provide mutual support.

Lessons Learned

Program Evaluation

The Caregiver Support Centre evolved out of the need for services and programs for caregivers, dimensions of elder care that had been noted by Case Managers within the CLSC René-Cassin/ISGQ. Ongoing research, rigorous methodological systems and the centrality of our dissemination mandate have assisted us in recently developing an evaluative framework that provides focused feedback. Vital to the Centre's overall success has been the determination of the impact of its programs and services on our caregiving community. This includes evaluating whether objectives have been met, whether the target population is being serviced and if that population is benefiting from the Centre's services.

Cultural Sensitivity

Services and programs for caregivers should be administered based on rigorous research into demographics, environmental variables and cultural sensitivities. The Caregiver Support Centre's initial development was the result of an expressed need for caregiver assistance. The Centre, thus, was ultimately guided by the validated needs of the community. Of late, however, we have noted the gap in research related to socio-economic, ethno-cultural and religious values guiding our community and have recently transformed the generalized need for services into an ethnoculturally sensitive service delivery program. Although the worth of caregiver programs is immeasurable, their value is largely determined by the needs of the population they serve. Methodological surveys need to be conducted on a regular basis in order to adequately prepare a program to meet the demands of the caregiver population it is intending to serve.

The Centrality of Volunteers and their Community Impact

The earliest phases of the Centre's development evolved without a true awareness as to the critical role to be played by volunteers in the Centre's overall success. With time, it became apparent that community involvement would redefine the depth of care and support afforded to our clients. Volunteers are needed on a daily basis to work in the Drop-in, the Foyer for caregivers, the In-Home Stimulation Program, The Caregiver Info-Line and in outreach activities. They are truly indispensable at the Caregiver Support Centre where the high level of dependency among participants often requires one-to-one care. The Caregiver Support Centre is fortunate to have a large number of volunteers working in its various programs. Some of these volunteers were originally caregivers using the Centre for their own respite needs. They volunteer at the Centre in order to give something back to the community and to the program that helped them through difficult times.

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Establishing a Community-Based Resource Center for Caregivers

Based on the model developed by

Family Caregiver Alliance

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Overview

Now nationally recognized for pioneering programs and services to support family caregivers, Family Caregiver Alliance was founded 25 years ago in San Francisco as the first voluntary, community-based organization to respond to the challenges of caring for loved ones with serious cognitive disorders striking after age 18. The organization recognized that the patient's family caregiver needed assistance and support, and developed a comprehensive range of services responsive to caregiver needs, regardless of patient diagnosis.

This community-based program is now replicated throughout California and is a model, in part, for the National Family Caregiver Support Program. The organization's structure allows us to provide innovative, comprehensive services directly to caregiving families with little red tape and, in most cases, little delay. Although originally FCA focused on cognitive disorders, recent Administration on Aging funding has allowed us to offer our services to caregivers caring for older loved ones affected by other chronic health conditions.

Our research has revealed that the three most common needs identified by caregivers are information, emotional support, and respite. These expressed needs have guided—and continue to guide—the development of all FCA services.

Current Structure, Funding & Client Base

Family Caregiver Alliance's core mission is "to support and assist caregivers through education, services, research and advocacy." In the FCA model, these elements are inextricably inte-

twined. Through a unique partnership between the private and public sectors, FCA assists a population previously excluded from aid through other sources. Services are especially designed for families who are above the eligibility limit for public benefit programs. There is no means test; services are provided to families based on the need for services. FCA funding comes from foundation grants, individual donations, from California State General Funds through the Department of Mental Health, from the National Family Caregiver Support Program, from the Administration on Aging, and from minimal fees for service.

FCA is a freestanding nonprofit organization governed by a 21 -member Board of Directors drawn broadly across the business, health, academic and policy fields. Many Board members are currently—or have been—caregivers, providing the consumer perspective. Staff (some multilingual) include family consultants, resource specialists, program associates and administration. In the diverse San Francisco Bay Area, we proactively reach out to ethnically and culturally diverse communities, including LGBT (lesbian, gay, bisexual and transgender) caregivers and other underserved populations.

Our clients are the caregivers. Seventy -six percent of caregivers are female—spouses, daughters or daughters-in-law of the care recipient. The average age is 60, with 24% between the ages of 36 and 50 years. More than half of the caregivers (52%) under the age of 65 also work outside the home, either full-time (41%) or part-time (16%). Nearly six in ten show clinical symptoms of depression. Our caregivers report they provide an average of 87 hours of care a week. (Source: California Caregiver Resource Centers 1999 Uniform Assessment Database.)

Program Description

Background

"During the course of my husband's illness, I found that I needed an awful lot of help. It was all so sudden, the problems so devastating, the legal affairs so overwhelming, that I needed help from every direction."

Suzanne Harris
Cofounder, Family Caregiver Alliance

In 1977, volunteers at a meeting of the San Francisco Mental Health Association were inspired to action and advocacy by the experiences of two women, Anne Bashkiroff and Suzanne Harris. Both women had become caregivers for their husbands who suffered serious cognitive disorders, and both were devastated by the overwhelming problems and the lack of services.

In 1978 the group received a special grant through the state Department of Mental Health as a result of task force meetings with officials in the state capitol and Washington, DC. The grant provided for:

- Conducting a needs assessment in the San Francisco community to determine the number of individuals with serious cognitive impairment, and the services available to them;
- Establishing a support network of families;
- Conducting a public awareness campaign; and
- Publishing a handbook of legal and financial information.

The volunteer task force found that the need for services was widespread and urgent. The group continued to pursue its cause with the California legislature. In 1979 landmark legislation passed which enabled FCA to develop a pilot project and to test service approaches for individuals and their caregivers.

The organization, originally called Family Survival Project, created support services for those struggling to care for loved ones who did not "fit" into traditional mental health systems: adults with Alzheimer's disease, Parkinson's disease, stroke, Huntington's disease, ALS, traumatic brain injuries or other cognitive disorders. The program grew as media coverage attracted the attention of families throughout the Bay Area.

In 1984, legislators—impressed with the successful program and in order to ensure that all Californians had access to these innovative services—passed The Comprehensive Act for Family Caregivers of Brain Impaired Adults, which established 11 California Caregiver Resource Centers (CRCs) throughout the state, replicating the FCA model. Each CRC serves as a single point of entry for information about care resources in its region.

In addition to its role as the San Francisco Bay Area Caregiver Resource Center, Family Caregiver Alliance was designated the Statewide Resource Consultant (SRC), to coordinate the system under the Department of Mental Health, to develop publications for consumers, to operate an information clearinghouse, design education programs, and to conduct research and document needs and services throughout the state. Today California remains one of the few areas with a statewide program which recognizes family caregivers across diagnostic lines and with broad definitions of disabilities and support services.

Methodology for Developing a Successful Project

Four principles guide the FCA model. These have stayed consistent throughout the 25 years the organization has been in operation:

- The family caregiver is the client.
- There is a broad focus across diagnoses.
- There is a fluid system of care, rather than a traditional caseload model.
- Family caregivers are the care managers for their impaired relatives.

FCA services enable caregivers to make knowledgeable, effective decisions and to learn skills that will help them become their own "case managers." FCA staff are not client or case managers. Staff offer emotional support, advice, information, and services such as respite care, which is brokered.

Our support program includes:

- **Direct Services:** A specialized FCA assessment tool allows family consultants to evaluate clients' situations, develop a package of services tailored to caregiver needs, and develop a database of invaluable information to enhance the growing body of knowledge about caregiving.
- The service package includes some or all of the following: telephone and e-mail consultations that provide families with specialized information and referrals; in-home psychosocial assessment; development of short- and long-term plans for the caregiving family; legal and financial counseling; access to regional databases of supportive services; individual, group and family counseling; support groups; Internet services; and respite services based on consumer direction and selection of service options. For some services, copayments (not to exceed the actual cost of services) are assessed from those able to contribute to the cost of care.
- **Education:** through publications, psychoeducational groups and classes, workshops, conferences, the Internet and other means, FCA educates families, policy makers, the media and health and service providers about the needs of caregivers and resources available to them.

- Research into caregiver needs informs the development of all new services that FCA undertakes. Longitudinal studies of caregiving over time, research into work and eldercare, consumer directed care, pre- and post-placement family caregiving and other studies have been completed. The studies fill gaps in the existing literature and offer us the opportunity to be on the cutting edge of new service systems.
- Advocacy: FCA provides information to legislative staff about long-term caregiving and supports legislative efforts to improve the quality of caregivers' lives. The National Family Caregiver Support Program was based in part on the FCA model.
- FCA utilizes technology as part of its service package. We use the Internet both to provide information and to deliver services. We operate two websites:
- www.caregiver.org, which includes our entire library of consumer Fact Sheets (many in three languages), our newsletter and other publications, as well as three online support groups and the means to contact our resource specialists for information and referral nationwide; and
- Link2Care, a secure, password-protected California-based website shared by clients statewide through our sister Caregiver Resource Centers offers online moderated discussions as well as "Ask the Expert" sections, journaling and other support and decision-making help.

Political/Financial Strategies

From the beginning, FCA's founders and staff recognized the close association between the development of effective caregiver services and the need for secure, substantial public funding through legislative action. As described above, the group actively advocated for their cause in the state capitol and made personal visits to legislators. Ultimately, they were successful in getting the support of then-Assemblyman Art Agnos, who introduced the bill (AB 1043) to secure the original funding and the subsequent funding for the statewide Caregiver Resource Center system (AB 2913). Some of our staunchest supporters now are legislators and past legislators who have personally experienced the challenges of long-term care within their own families.

Long-term caregiving is, of course, not a localized issue, but a societal one. The need for continuing advocacy work is clear, particularly in lean economic times. As Baby Boomers age, the numbers of families requiring assistance will dramatically increase; if funding is cut, more and more families will experience the isolation, exhaustion and depression that is common in caregiving families who are without support resources. More care recipients will be forced into early institutionalization and its concomitant high costs to the state. Our consistent message is that the state—any state—ultimately saves money by funding community-based caregiver services.

Barriers Overcome

- Initial lack of awareness of the problem. When FCA first began, "Alzheimer's" was not a household word. There were no daycare programs or respite programs, no support groups for caregivers. Nor was there quantitative evidence of the magnitude of the population that needed help. Media attention and formal public awareness programs have helped increase recognition of the challenges of caregiving and the size of the caregiving population.
- Shame and embarrassment among families, who were reluctant to make their private problems into public crusades. "Senility" was something to be hidden, and families assumed they should be able to cope with an ill family member on their own.

- Difficulty asking for help. For a generation raised in the Depression, asking for help or "charity" was considered a disgrace. Despite the enormous financial and emotional burdens of long-term care, supportive services had never been offered.
- Caregivers do not identify themselves in those terms. They consider themselves simply daughters, wives, husbands, partners, parents, siblings, or friends of someone who is ill, rather than an identifiable segment of society and providers of healthcare services. So services that address "caregivers" may not resonate—the connection may not be clear, and caregivers may not recognize that support services are meant for them. This has been somewhat ameliorated as media coverage of the issues continues.
- Two decades ago, professionals in the field needed training to understand the whole-family dynamic of caregiving issues. The breadth and all-encompassing nature of the challenges was perhaps not immediately apparent, nor was the need for support and services.
- The concept of consumer direction in the choice of services requested was an unfamiliar concept, although it has always been a part of the FCA program.
- Funding. Securing adequate funding for the vast array of services needed to assist families providing long-term care at home is an ongoing difficulty. For example, because of budget limitations, in the San Francisco Bay Area alone more than 600 families are on our wait list for respite services.

Keys to Success

All FCA service innovations are based on proven need: we ask our clients. Programs such as caregiver retreats, post-placement support groups, work and eldercare information, weekend camps for individuals with Alzheimer's, services for nontraditional families, multicultural and multilingual programs and others have resulted from discussions with our clients.

Respite is an essential feature in the FCA program, and indeed, limited funding for ongoing respite care—which includes a choice of adult day care, in-home care and registry or private pay arrangements—was secured in our initial state legislation in 1979. Innovative respite options, from caregiver retreats to weekend camps for care recipients (see chart on page 9) help us tailor a service package to each family's needs.

We hire knowledgeable staff and provide thorough training. The organizational culture welcomes innovation, creative solutions and new approaches to problems.

FCA's Caregiver Resource Center is recognized as a model program at state and national levels. A comprehensive operational manual developed by FCA assists new CRC staff and establishes consistent assessment methods throughout the state. Agencies and groups in many other states and countries have contacted FCA regarding replicating the CRC model.

Measuring Success

The efforts of FCA's earliest task force had three lasting results :

- The formation of Family Caregiver Alliance;
- The genesis of a first-in-the-nation statewide network of Caregiver Resource Centers; and
- The beginnings of a movement to recognize the immense contribution of family caregivers to the long-term health care of the ill and elderly in our country.

FCA has maintained its position in the forefront of long-term care programs. We currently serve caregivers at local, state and national levels:


- Our Bay Area Caregiver Resource Center (CRC), the focus of this guide, offers direct services to caregiving families in six counties in the San Francisco Bay Area. The ability to develop and deliver direct services at the community level remains of intrinsic importance to the agency, and offers us the opportunity to get feedback on the efficacy of new programs and to anticipate needs.
- FCA serves under contract as Statewide Resources Consultant for California's system of Caregiver Resource Centers—11 organizations which replicate FCA's model program.
- Building on FCA's formidable portfolio of national conferences, surveys, applied research, consumer publications and program development and replication, FCA established the National Center on Caregiving (NCC) in July 2001 with a grant from the Archstone Foundation. The Center serves as a public voice for caregivers and works to advance the development of cost-effective, high quality caregiver program in every state in the country.
- We have been granted funding from additional sources, in particular NFCSP funds through local Area Agencies on Aging, which have strengthened our services and broadened our client base.
- In acknowledgement of our professional credentials and the quality of our program, we receive numerous requests to present at conferences, provide technical assistance to other agencies and legislative staff, serve on advisory committees, and serve as media spokespersons. We have received a number of awards recognizing innovation in caregiving services.
- The number of requests for information and assistance continues to increase year by year as public awareness of caregiving issues grows.

Outreach Strategies

Although budgets are limited, we have utilized professional networking, technology, and public relations skills to reach caregivers. Our intake form tracks referral sources, which include other service organizations, rehabilitation facilities, discharge planners, media, families and friends. Our publications reach a large audience: the FCA newsletter, Update, is circulated to 20,000 readers and posted on our website each quarter. Materials are translated into Spanish and Chinese to serve multi-lingual communities. FCA's comprehensive, award-winning website is visited by nearly half a million people a year. We partner with organizations locally and nationally to develop and participate in caregiving-related programs. As our reputation grows, the requests for information have increased dramatically.

Community Coalition Building

Since no one organization can meet all the needs of long-term caregivers, it is essential—and mandated by law—that FCA and the other CRCs throughout the state coordinate activities with other organizations and services. We work closely with other programs to ensure that the greatest number of persons are served and the optimal number of organizations participate. We join with other groups to develop and sponsor educational programs, to advocate for critical policy developments (such as the recent move to pass legislation for paid family leave in California), and to nurture relationships to encourage referrals of caregivers to FCA for services.



As we continue to offer direct services for caregivers in the San Francisco Bay Area, we also offer technical assistance to our sister Caregiver Resource Centers in California, and currently, through our National Center on Caregiving and via the Internet, we provide information and assistance to caregivers, program developers, policy-makers and media throughout the country.


Lessons Learned

- Caregivers are the historians and managers of medical, social, legal and financial information, and choices for services should be in accordance with the values and preferences of the family and disabled adult. Families are seen as equal partners in the long-term care equation.
- FCA is committed to a standardized and comprehensive needs assessment which informs family consultants about the individual needs of caregivers, which in turn facilitates the crafting of specialized interventions. The assessment process also provides the opportunity to measure the effectiveness of FCA interventions over time through the baseline and follow-up assessment process.
- There are excellent programs for caregivers now in operation, and consultation is readily available as new programs are being developed. Rather than "reinvent the wheel," providers are encouraged to seek advice from established programs to reduce the incidence of problems and to build on one another's success.
- Caregiving is a public health issue of massive proportions. Not only the mental health but the physical health of caregivers is impacted; only now are physicians being encouraged to follow not only their patient's health status, but the caregiver's as well. The enormous costs of institutional long-term care dictate that family caregivers must be supported on every front, with a wide array of services and programs.
- We work within a public policy framework. States currently are major financiers and regulators of long-term care services. Policy issues such as paying family members for care, and caregiving's impact on the workplace affect the quality of caregivers' lives and their ability to continue to care for their loved ones. While progress is slow, an increasing number of states are replicating caregiver programs or initiating their own, and with the passage of the National Family Caregiver Support Program, federal agencies are taking note of this critical public health issue. FCA is pleased to be an advocate for the development of caregiver-friendly programs, both within our community and throughout the country.

For additional assistance, please contact Kathleen Kelly, Executive Director, or Lynn Friss Feinberg, Deputy Director, National Center on Caregiving.

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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

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

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Committee Members

Frances Barg, Family Caregiver Cancer Education Program, University of Pennsylvania; **Jane Barratt**, Carers Association of Western Australia; **Lia Susana Daichman**, International Network Against Abuse and Maltreatment of Elders; **Brian Duke**, Children of Aging Parents; **Steven Eidelman**, The ARC; **Elinor Ginzler**, AARP; **Amy Goyer**, AARP Grandparent Information Center; **Rick Greene**, Administration on Aging; **George Hopper**, Well Spouse Foundation; **Lennarth Johansson**, Swedish National Board of Health and Welfare; **Jill Kagan**, National Respite Coalition; **Ryoji Kobayashi**, Department of Humanities, Tokyo Metropolitan University; **Carol Levine**, Families and Health Care Project, United Hospital Fund; **Pedro Paulo Marin**, Geriatric Program Faculty of Medicine, Catholic University of Chile; **Katie Maslow**, Alzheimer's Association; **Suzanne Mintz**, National Family Caregivers Association; **Marja Pijl**, Dutch Carers Association; **Linda Schlachter**, Pfizer Inc; **Jeanette Takamura**, School of Social Work, Columbia University; **Melissa Talamantes**, Department of Family and Community Medicine, The University of Texas; **Cecelia Vergaretti**, National Mental Health Association; **Laura Trejo**, Los Angeles County Department of Mental Health; **Donna Wagner**, Gerontology Program, Towson University; **Myrl Weinberg**, National Health Council

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