Respite for Family Caregivers

An Environmental Scan of Publicly-funded Programs in Canada

Prepared for Health Canada

by

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Publicly-funded Respite Programs for Family Caregivers in Canada

Summary

Home care is an increasingly important component of the health care system in Canada. As family caregivers play a growing role in providing care, their need for respite, or time off, is also growing. The purpose of respite is to give the caregiver a break in order to avoid burnout or crisis, to enable the caregiver to take care of necessary activities outside the home, and to support a healthy relationship between the person receiving care and the caregiver. Respite can also provide a break for the person receiving care.

This report is an environmental scan of respite for family caregivers provided by publicly-funded programs in Canada at the federal, provincial and territorial level. Several types of respite programs are examined (in-home, facility-based, day programs, and so on) from the perspective of the user profile, eligibility criteria, cost to user, level of demand and special features, if any.

Demand is high for in-home respite because of early discharge from hospitals and the need or desire to care for a family member at home. Shortages of public funds for home care services and of home care workers were cited as the main reasons for the high demand relative to service availability. Demand for facility-based respite is somewhat lower (medium to high) and demand for day programs is high.

A high proportion of those requiring respite are the elderly spouses of elderly patients, many of whom are living on low incomes. The middle-aged children of the elderly constitute another sizeable group of family caregivers. Their challenges involve managing caregiving while fulfilling responsibilities to younger family members and to a job. Family caregivers of young children face many challenges; most public programs provide supplementary funding to help offset their costs. In all cases, respite hours during palliative care are not subject to time and cost ceilings, and are restricted only by the availability of resources.

Disparities of access to respite exist, based on income, geography or health condition of the patient. Mental health and services for those in rural and remote areas present gaps to be addressed. Implementation of the 2003 First Ministers' Accord will lead to the designation of minimum (core) home care services the will be fully paid by public health plans. If respite is designated as a core service, this may begin to fill existing gaps. A remaining challenge will be to develop enough home care workers to meet the demand for respite.

The public officials interviewed had a strong commitment to providing the best possible services for their citizens.

The report briefly summarizes the main findings from the environmental scan and provides detailed information on programs in a series of tables.

Publicly-funded Respite Programs for Family Caregivers in Canada

Context

Home care is an increasingly important component of the health care system in Canada. The 2003 First Ministers' Accord on Health Care Renewal provides for substantial investment in home care. Minimum home care services must be defined by the provinces and territories by September 2003. First Ministers agreed to provide first dollar coverage (i.e. totally funded by the provincial/territorial health plan) for the minimum (core) services for short-term acute home care, including acute community mental health and end-of-life care. Respite is currently a component of all public home care programs, which raises the expectation that it may be defined as a core service with first dollar coverage in all jurisdictions. The Accord also has as one of its statements of purpose that Canadians are able to access quality care no matter where they live. The 2003 Budget designated \$1 billion for a new federal compassionate leave program to begin in 2004 which will provide employment insurance benefits to people who take time off work to care for gravely ill family members. Family members will therefore become increasingly involved in providing care at home.

As family caregivers play a growing role in providing care, their need for respite, or time off from caregiving, is also growing. Respite provides time off from caregiving in order to relieve caregiver stress and burnout and to allow caregivers to attend to other areas of their lives. The consequences of not providing respite can include caregiver burnout, crisis, neglect and abuse. Federal, provincial and territorial governments acknowledge the need for respite. All publicly-funded home care programs in Canada have some provision for respite for family caregivers and some jurisdictions are currently reviewing respite provisions with a view to possibly enhancing them. The 2002 study by the Canadian Association for Community Care, *Give Me A Break!*, examined policy questions associated with respite for family caregivers. The study recommended the creation of a national caregiving strategy based on best practices, research, public education and an integrated policy framework.

In order to place these policy questions in the context of actual practice in Canada, Health Canada commissioned this environmental scan of publicly funded respite programs. The information in this report is intended to be a resource for federal, provincial and territorial officials and others dealing with respite issues. Programs described in detail in this report are those governed by policies at the federal, provincial or territorial level. Practice may vary somewhat at the sub-provincial or sub-territorial level depending on the model of service delivery determined by regional health authorities as they apply provincial or territorial policy to local situations.

Acknowledgements

Sincere thanks are extended to all the federal, provincial and territorial officials who provided information on their respite provisions and who took the time to verify and supplement the information in the tables at the end of this report. In all cases, officials were knowledgeable and helpful and showed a high degree of care and dedication to the clients they serve. Many were former health care providers who had first-hand

knowledge of the situations faced by families and who were dedicated to doing the very best they could for their clients within the funding and staff restrictions on home care programs. Thanks also go to the staff of the Home and Continuing Care Unit at Health Canada for their inspiration and help during the course of this study.

Methodology

The information in this report was gathered through interviews with federal, provincial and territorial officials working in departments of health and community or social services. Information from Quebec was not available at the provincial level and information was obtained from two well-regarded programs, one in Montreal and the other in the Estrie region centered around Sherbrooke. Websites of the relevant government departments were also consulted, as was documentation provided by some officials. Information in the appended tables was verified by government officials in the program described.

Scope

This environmental scan examines the following types of publicly-funded respite: inhome services; facility-based respite; day programs; programs for rural and remote areas; palliative care; adults with disabilities; children; and mental health. The report also includes user profiles, eligibility criteria for programs; cost to the user; level of demand for the respite service relative to service availability; and a description of special features, if any. The final section of the report consists of tables detailing the respite programs of each jurisdiction. All provinces (with the exception of Quebec at the provincial level) and territories, Health Canada (First Nations and Inuit Health Branch) and Veterans Affairs Canada participated in the study.

This study covers only respite services that are included in publicly-funded programs, with some mention of voluntary sector programs that may receive some government funding. In many jurisdictions, families whose income is above a defined threshold may hire private services to provide respite because they wish to hire privately or because they are not eligible for assistance under the provincially-funded program.

Definitions

For the purpose of this report, **respite** is defined as a break, time out or relief for the caregiver. In most cases, this is provided through a home care worker coming to the home to allow the family member time off, or through placing the patient in a respite bed in a long-term care facility for a short-term stay (usually 30 days or less). A **family caregiver** is defined a person who considers themselves to be a primary caregiver and who is providing care because of a prior relationship with the client. They may be members of a biological family or a "family of choice" (friends, partners, neighbours).

Most provinces and territories define respite and family caregiver in a way that is substantially the same as these definitions. Some provinces, such as Nova Scotia, stress that respite for caregivers of children includes the element of facilitating a positive

¹ Canadian Association for Community Care: *Give Me A Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite,* 2002 and M. J. Hollander and E. R. Walker, *Report of Continuing Care Organizations and Terminology,* 1998.

and rewarding experience for the child and strengthening families by reducing stress. This philosophy is shared by other jurisdictions. Prince Edward Island suggested that respite also provides a break for the care recipient. Alberta is the only jurisdiction that restricts the definition of family caregiver to relatives (including those related through marriage or common law), trustees or guardians.

Respite is provided through a variety of means, including: the in-home presence of a homemaker which allows the family caregiver time away or time off; facility-based respite which is usually provided by a residential care facility (or more rarely, by a hospital) for a defined period; and day programs for the person receiving care. In some cases, such as the program provided by the CLSC² René-Cassin in Montreal, respite programs are considered to include support groups for family caregivers, telephone support, information sessions, counselling, and other services. Newfoundland and Labrador and Alberta also include the possibility that a paid homemaker could provide respite by helping the caregiver with such things as shopping. Informal arrangements such as this probably occur in many jurisdictions.

All jurisdictions agreed that respite does not apply to paid caregivers and some stated that respite is not intended to free the caregiver to take paid employment.

Most family caregivers are elderly spouses, middle-aged children of the elderly, parents of children and youth who are severely ill, disabled or developmentally delayed.

Main Findings

User profile

For all forms of respite other than child or mental health care, caregivers needing respite are mostly elderly spouses and middle-aged children or siblings and other relatives of the elderly. Caregivers of adults with disabilities or persons living with mental health conditions may be young to middle-aged parents or spouses. Caregivers of young children are usually young parents. In many jurisdictions, more than 90% of home care recipients are over the age of 65 (Montreal, Ontario, veterans) and their caregivers tend to be elderly spouses. In northern Canada, a higher proportion of clients receiving home care are under age 65 (roughly 40% in Yukon) and living with developmental delays, early onset Alzheimers and multiple sclerosis, mental health conditions and disabilities.

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² A CLSC is a *Centre local de services communautaires* (local community service centre) and is funded by the provincial government through the regional health authority. There are 147 CLSCs in Quebec.

Cost to user

Policies vary across Canada with respect to the cost of respite. In some jurisdictions, there is no direct cost to the user for in-home respite (Ontario, Manitoba, Yukon, Northwest Territories, Nunavut, First Nations and Inuit Health Branch programs, Veterans Affairs Canada programs). In others, income or income plus assets are assessed in determining eligibility for services (Newfoundland and Labrador, Nova Scotia, Prince Edward Island, New Brunswick, Quebec, Saskatchewan, Alberta. British Columbia) and the proportion of costs to be shared by the family. A high proportion of clients receiving public services in some jurisdictions (e.g. 95% in Nova Scotia) do not pay fees because of their low incomes. Saskatchewan and Alberta have a monthly cap on the amount paid by the client (\$61 - \$360/month in Saskatchewan and \$300/month in Alberta) after which the public system covers costs (to a maximum of \$3000/month for all home care in Alberta). In most cases, those with incomes above the defined threshold must pay a portion of costs ranging up to 100%. Those with sufficiently high incomes in some jurisdictions must hire their own services independently of the public system (e.g. Newfoundland and Labrador) although the public system may help families find qualified personnel (Nova Scotia, Ontario). In northern Canada, there are no private agencies and all residents with health care coverage receive services under the public plan at no direct cost.

Policies with respect to direct costs for respite for family caregivers of the disabled or children follow the same pattern, with supplementary allowances often paid by the provincial/territorial government to offset the cost of care, supplies and drugs.

All jurisdictions except Nunavut require the client to pay a portion of the cost of facility-based respite, usually in a long-term care facility. The amount may vary according to income, with most rates in the range of \$800 - \$900/month (roughly equivalent to the Old Age Security Guaranteed Income Supplement [OASGIS]). This may cause financial difficulty if the client's normal accommodation at home is also paid from their OASGIS income.

Caregivers of those receiving palliative care are allowed extended respite hours under public plans, with the amount being limited only by the availability of resources. In these cases, cost ceilings may be exceeded, with the extra cost being covered by the public system if clients qualify for financial assistance in jurisdictions with means tests.

Day programs usually charge a small fee to cover the cost of a meal and transportation, ranging from \$5/day to \$30/day across Canada, with most costing less than \$10/day.

Respite programs funded by Veterans Affairs Canada normally do not charge fees to users, with the exception of respite beds in a long-term care facility where the client may be required to contribute to the cost of accommodation and meals.

Only programs funded by the First Nations and Inuit Health Branch of Health Canada have any specific provision for supplementary funds for remote or isolated communities, although no respite programs charge a direct cost to the user. In all other jurisdictions, residents of rural and remote areas are covered by the same policies with respect to cost as other provincial/territorial residents.

This study reveals that direct-cost-to-user policies vary widely across Canada, particularly with respect to in-home respite. Although some provinces have low income thresholds (e.g. Newfoundland and Labrador has an income threshold of \$5000 in liquid assets for an individual or \$10,000 for a couple above which clients must purchase services), in fact most clients may be receiving services at no direct cost because most have low incomes (e.g. 95% of home care clients in Nova Scotia do not pay for services). In many jurisdictions, therefore, publicly-funded plans are serving mainly those with the lowest incomes while those with modest or abundant means are hiring their own services on the private market independently or with the assistance of provincial agencies that act as brokers to bring together clients and accredited paid care providers. Many seniors or others on limited incomes have stated that the amounts they are required to pay for in-home respite or a respite bed in a facility present an insurmountable financial barrier³ and they must do without respite. Disparities in access to respite based on income both within jurisdictions and between jurisdictions are subjects for ongoing study and discussions on equality of access to services in Canada.

In-home respite

In-home respite is provided for family caregivers by a home support worker coming to the home for a number of hours to give the caregiver time off. During this time off, the caregiver may remain in the home or leave. No jurisdiction restricts the activity that the caregiver may undertake during this respite time, although some explicitly state that inhome respite is not intended to allow the caregiver to undertake paid work (e.g. Yukon).

In all cases, the need for respite is assessed by a case manager as part of the overall care assessment for the patient and family. The usual respite period taken is a block of 2-4 hours once or twice a week. Some jurisdictions have a monthly maximum number of respite hours (e.g. 40 hours – Nova Scotia) or a monthly financial ceiling on total home care expenditures, including respite (approximately \$3000 – Newfoundland and Labrador; Alberta) except for palliative care which allows for these limits to be exceeded. In all cases, availability of respite depends on the availability of home care workers. Demand for in-home respite is rated as high by most jurisdictions. The province of Newfoundland and Labrador is currently accepting new clients for home support on an emergency basis only because of limited resources. Reasons cited for high demand are early discharge from hospital with high caregiving requirements at home, limited budgets and the shortage of home care workers to provide care or respite.

Financial eligibility for services, or the portion of cost borne by the family, is assessed in some jurisdictions (Newfoundland and Labrador; Nova Scotia; New Brunswick; Quebec; Saskatchewan; Alberta; British Columbia) and not in others (Ontario; Yukon; Northwest Territories; Nunavut; First Nations and Inuit Health Branch, Health Canada). In assessing financial capability, income is always considered and in most cases, assets. The exceptions are Prince Edward Island and British Columbia, which consider only income and not assets. The determination of need by a case manager includes consideration of such things as the family's financial and psychosocial capacity. In all cases, those with the means to hire respite services directly can do so. In regions such as the Northwest Territories, however, there are no private agencies and all services are provided by the territorial government.

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³ Canadian Association for Community Care: Give Me A Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite, 2002.

Some jurisdictions provide home support workers for respite. In others, the client may hire a worker directly (Newfoundland and Labrador; New Brunswick) or hire from a number of workers suggested by the provincial program, wherein the provincial program acts as a broker to bring qualified workers and families into contact (Nova Scotia; Ontario). In all jurisdictions except British Columbia, an immediate family member cannot be hired. British Columbia will allow payment to family members not residing with the client, excepting a parent, child or spouse. Under exceptional circumstances (rural and remote location, cultural or language barriers, and behavioural problems) spouses, parents and children may receive payment if no other qualified caregiver can be found. The number of available home care workers is limited by public funding to hire them and a shortage of workers. Problems cited by some jurisdictions include the difficulty of finding home care workers who will work for a documented salary rather than cash.

Facility-based respite

All jurisdictions provide for facility-based respite, with the usual period being 30 days, although shorter periods such as weekends or 14-day periods are possible. Some jurisdictions have a maximum annual number of days ranging from 28 if on public assistance (Nova Scotia) to 60 days (most jurisdictions) with extensions possible in special circumstances. Some provinces note that if facility-based respite extends beyond 60 days/year, the patient probably needs to be in a long-term care facility (e.g. Saskatchewan). In some cases, respite beds may be available in hospitals, but this appears to be uncommon. Hospital respite beds may be used in regions where there are few long-term care facilities (e.g. rural Manitoba).

The share of costs paid by the family for a facility-based respite bed varies widely from \$8/day (Montreal) to \$147/day (Nova Scotia – can be offset by financial assistance) with most costs in the range of \$30/day or \$800/month (this represents roughly 25% of the cost in many cases with the balance being paid by the province or territory). In most cases, the family usually pays the lowest amount charged by the facility which is often roughly equivalent to the Old Age Security Guaranteed Income Supplement for seniors.

The level of demand for facility-based respite ranges from high (Montreal; Manitoba; Saskatchewan; British Columbia; Nunavut) to medium (Nova Scotia; New Brunswick; Ontario; Northwest Territories) to low (Northwest Territories). In southeastern Quebec (Estrie region), 36% - 80% (depending on the sub-region) of temporary stays in long-term care facilities are for respite. Demand for facility-based respite may be lower than for in-home respite because of the patient's or family's fear that entering a long-term care facility will result in a permanent stay in the facility (anecdotal reports from those interviewed).

First Nations and Inuit communities make little use of off-reserve facility-based respite beds because the patient's health often declines when they are removed from their community and cultural context. Some of the large Ontario reserves do have long-term care facilities which can offer respite beds, but this is uncommon.

Day Programs

Day programs are offered in most jurisdictions with a mix of public and voluntary sector services. Newfoundland and Labrador, New Brunswick, Montreal, Manitoba, Saskatchewan, Alberta, Yukon, Northwest Territories and Nunavut all have day programs in publicly-funded facilities. In most cases, voluntary sector programs (Alzheimer's Society; seniors' and children's programs; programs for the disabled) receive at least a small amount of public funding (except in Nova Scotia). Some day programs are used by family members who want to continue working. Very few First Nations communities have day programs.

Day programs usually charge a small fee to cover the cost of a meal and transportation (less than \$10). Fees can often be waived if the user's income is low, or paid according to a sliding scale based on income. Day programs can be used from 1-5 days a week, but demand is high in most jurisdictions with frequent wait lists. High demand limits the number of days per week that an individual client may use the program. Montreal, British Columbia and Northwest Territories rated demand as medium. Lack of flexible hours has been cited as a barrier to respite by family caregivers. Only one day program surveyed (CLSC René-Cassin, Montreal) explicitly stated that it offered flexible hours, although some day programs in other regions are operated on a drop- in basis and some Alberta day programs operate in the evening. Other day programs, largely offered by voluntary sector organizations, may also offer flexible hours, but an in-depth survey of day programs offered by these organizations was beyond the scope of this report.

Palliative Care

In all cases, the provincial or territorial home care plan allows for extended respite hours during palliative care, with the only limit being availability of resources.

Rural and Remote Areas

In all jurisdictions, family caregivers living in rural or remote areas are covered by the same respite programs available to those in urban areas. The only special provision for isolated communities is that of the Home and Community Care Program funded by the First Nations and Inuit Health Branch of Health Canada: additional funds can be allocated to isolated communities. Most jurisdictions cited the difficulty of recruiting enough home care workers in rural and remote areas because of the smaller labour pool in these areas and the long distances that must be travelled (sometimes by plane). Facility-based respite care for those in rural and remote areas is often available only in the nearest large centre, which may require the patient to be far from home and may possibly entail a high cost in time and money for the family caregiver who wishes to visit the patient.

Adults with Disabilities

Many jurisdictions provide respite for caregivers of adults with disabilities under the provincial/territorial home care program. In other jurisdictions (e.g. Ontario) home care for the disabled is often provided through the programs of community service divisions of provincial ministries, rather than by health care services.

⁴ Canadian Association for Community Care: *Give Me A Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite*, 2002.

In some cases, the total monthly home care allowance including respite for those living with disabilities, is higher than that allowed for regular home care (Newfoundland and Labrador). Policies are variable with respect to income as a component of needs assessment. Day care programs for the disabled are often provided at no cost to the user, given their low incomes.

Children

Children are defined as being under age 18 or 19 by the provinces and territories. Many jurisdictions differentiate between children with illness and those living with disabilities in terms of which programs or ministries are responsible for supporting the children and their families. Many jurisdictions have supplementary funds for child home care in addition to home care budgets to provide additional care, family support, drugs and supplies. Jurisdictions that estimated the level of demand for respite services for caregivers of children rated demand as high, citing a scarcity of care workers, particularly for disabled children. Early discharge from hospital and consequent high home needs was cited as another reason for high demand. Demand for facility-based respite was rated as only medium because of the desire by families to keep children at home if possible.

Facility-based respite for family caregivers of children tends to be in a foster home or government-provided apartment (e.g. Nova Scotia). Length of stay in a facility is shorter than for adult patients, with stays as short as one night or a weekend being possible. Ontario, Manitoba, Yukon, Northwest Territories and Nunavut provide respite as part of care at no cost to the family. Other jurisdictions offset costs with an allowance to the family which is proportional to income or ask families to contribute directly to costs on a sliding scale geared to income.

Canuck Place in Vancouver, Canada's only residential palliative care hospice for children, offers 20 days a year per client in a respite bed. Canuck Place, however, is largely supported by charitable donations and receives only minimal government funding.

Mental Health

Many jurisdictions do not have designated respite services for family caregivers of those living with mental health conditions. The Commission on the Future of Health Care in Canada (the Romanow Commission) identified mental health care as a significant gap that needs to be filled. The 2003 First Ministers' Accord on Health Care Renewal named acute community mental health care as an important component of core home care services.

The situation in terms of home care for those living with mental health conditions is somewhat different from that of physical illness or disability. In many cases, families are not caring for a family member living with a mental health condition because the person is living in supportive housing or may be homeless, or because relations have been severed with the family. In other cases, mental health conditions may be invisible but still require significant family caregiving. A spouse living with depression may create a burden on the other spouse to provide care and support as well as dealing with child care and the other demands of running a household. Since more women than men are diagnosed with depression, the men who are their spouses may constitute an invisible group of family caregivers who are not obtaining respite. Fear of social stigma may deter

families living with these conditions from seeking help. In many cases, there may be no respite available under the public health plan. Lack of a break from the situation may have a damaging effect on family dynamics, particularly as they affect children.

Some provinces offer day programs that focus on activity, treatment or therapy rather than respite (e.g. Prince Edward Island), and respite is an indirect result of such programs when the person lives with their family. In some cases, mental health clients are eligible for the same home care services as those living with physical illness, based on assessed need. In other cases, mental health clients are only eligible for general home care programs if they also have a physical disability or illness (e.g. Newfoundland and Labrador). Yukon provides mental health respite beds in Whitehorse, and Nunavut has a transitional facility in Iqaluit with limited respite opportunities. In most cases, demand is rated as high relative to available services. Respite for family caregivers of those living with mental health conditions appears to be a gap that needs addressing.

Federally-funded respite programs

First Nations and Inuit Health Branch, Health Canada

The new Home and Community Care Program announced in the 1999 Budget is currently being developed across Canada. Each First Nations and Inuit community will define its services under the program, with some elements being designated as essential and others as supportive service elements (secondary services). In-home respite is defined as an essential service element under the program. The First Nations and Inuit Health Branch (FNIHB) of Health Canada is responsible for working with communities to develop their services. Once a community service plan has been approved and is implemented, the community will manage the program and FNIHB will play an advisory, monitoring and funding role for the program.

Facility-based respite, day programs and palliative care are designated as supportive service elements rather than essential elements. FNIHB does not currently have a mandate to provide these services. An estimated 50% of communities may offer in-home respite care, depending on local needs and conditions. Very few communities offer facility-based respite or day programs. Unless long-term care facilities are located in the community or in an Aboriginal cultural context, they are unlikely to be used for respite. Experience shows that Aboriginal clients suffer health decline in facilities that are far from home and not culturally appropriate. An ongoing challenge in providing care and respite is the need to train health care workers.

In the North in particular, there is a strong degree of integration of provincial/territorial health care services and Health Canada (FNIHB) and Department of Indian and Northern Affairs health care services because of the large First Nations and Inuit populations.

Veterans Affairs Canada

Veterans Affairs Canada (VAC) is a significant provider of respite services for family caregivers of veterans and those with disability pensions. The purpose of VAC respite services is to avert caregiver burnout or crisis before it occurs. The average age of veterans is currently 79. The principal family caregiver in many cases is an elderly spouse. Based on a needs assessment, VAC will provide time off for the family caregiver and help with household upkeep and maintenance (including outdoor maintenance). The annual maximum entitlement for all respite services is 59 days, which may be extended during palliative care. Some day programs are available, especially in cases of dementia. All services are normally provided without direct cost to the user. VAC services are intended to supplement and complement services available in the community and those provided by provincial/territorial health plans.

Conclusion

Based on the findings of this study, officials in all jurisdictions recognize the crucial need for family caregiver respite and want to provide the best possible services for their citizens. They are often constrained in doing so by limited financial and human resources. In spite of constraints, all jurisdictions have provision for family caregiver respite.

The availability of respite across Canada varies widely depending on provincial/territorial financial resources and the availability of qualified workers. Respite availability also varies within jurisdictions when low-income families may be unable to afford the cost, even though they receive some public assistance. These situations create disparities for family caregivers based on income and resource availability.

There are some reasons for hope of improvement. The First Ministers have stated in their 2003 Accord on Health Care Reform that Canadians should have access to quality care no matter where they live. The availability of in-home respite in particular may need to be addressed to ensure that equality of access can be achieved. The designation of respite as a core home care service and consequent provision of first-dollar coverage would be an important step in this direction, as would increasing the pool of qualified home care workers.

Demand is high for respite, especially for in-home respite and day programs. As the Canadian population ages, demand will continue to grow. In light of the new compassionate leave plan that will come into effect in 2004, there may be an expectation by public officials that family members must leave work to provide a greater share of caregiving. Reducing income barriers and increasing health human resources for respite are crucial if family caregivers are to bear up under the load of providing care. The consequences of not providing respite can include caregiver burnout, crisis, neglect and abuse.

Demand for facility-based respite is somewhat lower than for in-home respite; if fears of permanent placement could be alleviated, respite beds might be more fully used. Day programs are currently provided largely by the voluntary sector with wait lists in many cases. Increased public funding could help to expand capacity and absorb demand for day programs. Provinces and territories could consider whether day programs should be

viewed as part of a total approach to home care because of their benefit to both the patient and the family caregiver.

Gaps appear to exist in respite for family caregivers of those living with mental health conditions. Under the 2003 First Ministers' Accord, this area will receive further attention. Canadians living in rural and remote areas also appear to be disadvantaged in many cases relative to those living in urban areas. Their needs require further examination.

Federal/Provincial/Territorial Respite Services

The attached tables provide details of respite services available in all provinces and territories. Service details are also given for the Home and Community Care Program funded by the First Nations and Inuit Health Branch, Health Canada and for programs provided by Veterans Affairs Canada. The User Profile in the tables describes the caregiver receiving respite rather than the patient receiving care.

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|----------------------------------|---|--|--|--|--|--|
| In-home services (seniors) | Home support program: Home support worker in home to give caregiver time off. Eligible hours/month are based on assessed need up to allowable amount (\$2,707/month). | Spouses of seniors and their middle-aged children who provide care | Respite eligibility based on needs and financial assessment Must have \$5000 or less in liquid assets/single and \$10,000 or less for a couple (above this threshold, client must purchase services). | Eligible individuals can access up to \$2,707/ month for all home support services. According to their income and need requirements, individuals may have to contribute to the cost of the home support service. If the individual is not eligible they may hire privately. The approved hourly rate for home support is \$7.29. | High Because of limited resources, new clients have access to emergency services only. | Client may hire own home support worker or purchase service through approved agency; immediate family members cannot be hired. |
| Facility- based respite | Up to one month per year or more often under special circumstances. | Caregivers of seniors who require extensive assistance | Available to seniors with respite need manager | \$20/day | | |
| Day programs | Day Programs are community or institutional based service that | Caregivers of frail elderly, socially | Must have some type of physical disability. | \$3 to \$30/ day | High Limited number of spaces | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|--------------------------|--|--|--|--|--|--|
| | provides personal care, meals and transportation. | isolated seniors | Financial assessment is completed to determine payment. | | available. | |
| Rural and remote areas | Same programs as rest of province. Level of service depends on local resources | | | | | |
| Palliative Care | Respite services may be provided at higher levels for palliative care (e.g. longer in-home respite hours). | | | | | |
| Adults with disabilities | Home support worker comes into the home to give the caregiver time off. The worker performs all required functions (e.g. personal care, home making and home maintenance). The | Elderly parents and paid caregivers | Respite eligibility based on needs and financial assessment of the individual. Must have \$3000 or less in liquid | No cost within allowance limits (\$3875/month) if needs assessment determines financial eligibility. | High Because of limited resources, new clients have access to emergency services only. | Many persons with disabilities choose self- managed care under which they hire their own services. Funding |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|--|---|---------------------------------------|--|---|--------------------|---|
| | number of hours varies according to the individual's assessed need up to the \$3,875/ monthly allowed amount. | | assets/single and \$5,500 or less for a couple(above this threshold, individual must purchase services). | | | maybe provided for them to hire a book- keeper to perform payroll functions. Immediate family members cannot be hired. |
| Children with disabilities (aged under 18) | In-home and residential respite is available through the Special Child Welfare Allowance Program. Hourly respite is available according to assessed need. Residential respite is usually provided in an approved caregiver (foster) home for periods of overnight (maximum of two | Parents of children with disabilities | Any family who has a son or daughter with a disability living at home. Eligibility based on family income (liquid assets less than \$5500) and needs assessment. | Funding can be used to offset in-home support or respite time in an approved caregiver(foster) home. Caregiver home rates (based on individual needs) are up to \$1038/month – pro-rated for shorter periods to cover daily/weekly/week-end periods. Funding approved monthly varies according to demonstrated need | | Families may hire own hourly home support worker or purchase service through approved agencies; immediate family members cannot be hired. Funding for |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|--------------------|--|-----------------|-------------------------|--|--------------------|---|
| | nights); weekend or extended (3-day) weekend; weekly or monthly. | | | and financial eligibility but is within the ceiling for home support for adults with disabilities. | | book-keeper services may also be available if required. |
| Mental health | No specific programs. Covered by community support program only if patient has a physical illness or disability. | | | | | |

Note: In Newfoundland and Labrador, respite is defined as a break, time out or relief for the caregiver. In most cases, this is provided through a home support worker coming to the home to allow the caregiver time off. Respite is also achieved when the home support worker accompanies the individual to community activities. Residential respite includes the use of short term stays in long term care facilities for seniors and in approved family homes for children and adults with disabilities.

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|-------------------------------|---|---|--|---|---|--|
| In-home services | Maximum of 40 hours/month. Determined by need and availability of homemaker resources. Respite is provided by staff from Continuing Care's contracted service provider agencies. There is no direct funding to the family. | Elderly spouses; middle-aged children of elderly; spouses and family of middle-aged. | Determined by case manager's assessment of need. | There may be a client fee charged. Fees are assigned on a sliding scale and based on income. Maximum monthly fee would be \$320 for 40 hours of inhome respite. | High | More than 95% of clients do not pay fees. Services provided by not-for-profit agencies such as VON under contract with the Department of Health. |
| Facility- based respite | 91 respite beds in province (Department of Health facilities); 85 in Nursing Homes, 6 in Residential Care Facilities 1 in Nursing | Elderly spouses; middle-aged children of elderly; spouses and family of middle-aged. | Private pay clients may contact facility directly. Clients seeking public assistance must undergo both a care needs assessment and a financial | LTC facility sets per diem charge for respite beds. Majority of facilities charge same per diem that is approved by Department of Health for regular | 40% occupancy rate July- Dec, 2002 | Approximately 60% of those admitted to long-term care for respite are admitted to regular LTC beds upon discharge from respite beds. |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|--------------------|--|---------|-------------|--|----------|----------|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | Home children's unit up to 28 days/year if receiving public assistance | | assessment. | beds. Average per diem is \$147. If a client cannot afford to pay the full cost, they may be publicly subsidized for some portion of the costs, based on income and assets. | | |
| Day programs | Run by voluntary sector in many regions. There is no formal provincial funding. There has been ad hoc grant funding in the past. | | | | | |
| Palliative Care | Extra respite hours may be provided during palliative care through home care. Long-term care facility beds are | | | | | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|--------------------------|---|----------------------------------|--|--|---|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | sometimes used for palliative care. | | | | | |
| Disabled | Day programs in 30 centres | | | | | |
| Children (0-19 years) | 1. In-home respite covered by the Home Support Program for Children (Department of Community Services). The programs screen respite care providers and match them with families. | Parents and families of children | Caregivers of children who have a significant developmental delay or physical disability with ongoing functional limitations as a result of the disability and/or children with extraordinary health care needs. Family must meet income guidelines. | No fees for inhome respite if the family meets income criteria. Families pay for the caregivers out of their respite funds (\$3600/year to cover respite, drugs and supplies: amount allowable for respite determined by assessment of respite needs of child and family). | Respite programs: medium to high demand | Program also covers drugs and supplies. Program seeks and screens care workers, provides 2-3 names of workers to family who in turn hires the worker for respite. |
| | 2. Out-of-home respite Each of 4 health regions in Nova Scotia has an | | | 2. Out-of-home respite (24-hour care for the child) must be paid for | | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|---------------------------------------|---|---------|-------------|---|----------------------------|---|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | apartment available for weekend respite. Must be booked ahead. Family hires worker to provide 24-hour care for child while in out-of- home respite. | | | by the family from allocation provided by Home Support Program for Children (see above) | | |
| Rural and remote areas Mental health | Same programs as rest of province. Facility-based respite provided in nearest centre. No specific respite programs | | | | High relative to resources | Ministry of Health contracts with agencies to provide services. |

Note: The Family Caregivers' Association of Nova Scotia supports the following definitions of a "caregiver" and/or "family caregiver":

A family, friend or neighbour who provides support and care to family or friends who are physically or mentally challenged, chronically ill or frail and elderly either at home or in a care facility. Family caregivers provide care to all age groups, regardless of the care receiver's disease or disorder as well as palliative situations. Caregivers are spouses, adult children or in-laws, siblings, young children, and other extended family members or friends. Caregivers have a special relationship with their care receivers. (FCgANS working definition)

Children: Respite care is to relieve the parent/family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a disability or a chronic illness. Respite care includes: meeting the care needs of the child; offering the child opportunities to develop social recreational and life skills; strengthening families by reducing stress and thereby improving long-term function and qualify of life.

THE FOLLOWING ARE THE POLICY REFERENCES TO RESPITE FOR THE DEPARTMENT OF HEALTH IN NOVA SCOTIA:

Community Supports for Adults Policy Manual - Chapter 2, Policy Number 2.5.1

"Respite care can provide primary caregivers with the necessary support services in cases of emergency, or vacation periods or sporadic breaks (e.g. weekend for caregivers."

"Community Supports for Adults facilities may offer respite care for a planned period of temporary care to persons who normally reside at home and who are dependent on family members for intermittent or continuous care..."

Home Care Nova Scotia - Policy and Procedures Manual - Chapter 4, Section 4.09.01

Family Relief is service provided at home, by Home Care Nova Scotia, for short periods of time. The objective of Family Relief is to support the family environment by allowing caregivers time to attend to personal matters or to obtain needed rest and relief. Family Relief may include the services/supervision normally provided by the primary caregiver(s). Family Relief is not provided to paid caregivers.

Children: definition of respite: Respite care is to relieve the parent/family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a disability or a chronic illness. Respite care includes: meeting the care needs of the child; offering the child opportunities to develop social recreational and life skills; strengthening families by reducing stress and thereby improving long-term function and qualify of life.

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|-------------------------------|--|--|--|---|-------------------------------------|---------------------|
| In-home services | Visiting homemaker provided by Home Care Support Program. Maximum 4 hours/day. Depends on available resources. | Elderly spouses; middle-aged children of elderly; parents of children who are ill or who have special needs. | Income taken into account, but not assets. | Sliding fee scale (means tested) from \$0 - \$13/hour. | High | |
| Facility- based respite | 10 nursing home beds available across province for those at high care level. Maximum stay is 30 days/year (can be broken into smaller periods). | | Patient must require high level (level 4 or 5) of care | Per diem fee equivalent to OAS/GIS | Medium to high | |
| Day programs | Voluntary sector programs in urban areas for seniors, Alzheimers, mental health (see below). Some public funding for these programs. | | | Usually \$5/day | High demand and wait lists | |
| Palliative Care | Respite hours may be extended for palliative care. | | | | Medium to high | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | level of | SPECIAL |
|--------------|-------------------------|-----------------|-------------------|------------------|--------------|--------------------|
| PROGRAM | | PROFILE | CRITERIA | USER | demand | FEATURES |
| Children | Respite available | Caregivers of | Caregivers of | Individuals and | High | The PEI Disability |
| and Adults | under the PEI | individuals | children and | Families | demand; | Support Program |
| with | Disability Support | with a | adults up to age | receive | respite | was implemented |
| Disabilities | Program. This | physical, | 64 years with a | funding and | providers | in Oct. 2001. |
| | program is designed | intellectual or | physical, | hire their own | difficult to | This program de- |
| | to assist Islanders | neurological | intellectual pr | respite | find. | linked disability |
| | who have a qualifying | disability. | neurological | providers. | | supports from |
| | disability to overcome | | disability. If a | | | income support |
| | barriers, to attain a | | person turns 65 | Individuals and | | programming. |
| | satisfactory quality of | | when they are | families are | | |
| | life, and to strive to | | receiving | expected to | | *Under income |
| | achieve financial | | supports, their | pay a portion | | support |
| | independence. The | | supports and | of the cost of | | programs |
| | program offers | | their eligibility | services and | | disability |
| | disability supports | | will continue. | supports | | supports are lost |
| | based on specific | | | needed based | | when the income |
| | needs of individuals | | Individual | on their ability | | reaches a certain |
| | and families. | | situations are | to contribute. | | level that |
| | | | assessed to | | | terminates |
| | | | determine | Client | | someone from |
| | | | needs and level | Contribution | | Income Support |
| | | | of respite | calculation: | | Programs. Under |
| | | | support | | | PEIDSP, some |
| | | | required. The | Adjusted Net | | level of support |
| | | | full array of | household | | for disability |
| | | | family and | income (from | | specific needs is |
| | | | community | Canada | | available for |
| | | | supports is | Customs and | | individuals and |
| | | | considered in | Revenue | | families with |
| | | | the | Agency, Notice | | higher incomes. |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | level of | SPECIAL |
|------------------------|---|---|--|---|----------|--|
| PROGRAM | | PROFILE | CRITERIA | USER | demand | FEATURES |
| | | | assessment. | of Assessment), less \$3000. for each dependent under age 25. A monthly contribution is determined from a client contribution schedule. Assets are not reviewed. | | |
| Children | | | | | | |
| Rural and remote areas | Same programs as rest of province | | | | | |
| Mental health | Two day programs in Queens County (McGill Centre and Hillsborough Hospital) with focus on treatment/therapy rather than respite. Two respite beds in Hillsborough Hospital for clients who would | Caregivers of clients with a mental health need and stable in the community setting. Programs described are for the seriously and | Client is stable in the community setting. | No cost | | Day programs and respite beds are not designated as a mental health respite programs but do provide respite for family caregivers. |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | level of | SPECIAL |
|---------|--|-------------------------------|-------------|---------|----------|----------|
| PROGRAM | | PROFILE | CRITERIA | USER | demand | FEATURES |
| | be hard to place if caregivers were not given the option of respite. | persistently mentally ill. | | | | |

Note: Respite is defined as also a period of relief or a break for the care recipient.

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|--------------------|--|--|---|---|--|---|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | | | | |
| In-home | Long-Term Care Program: Depending on needs, a few hours of respite service is provided by a Home Support Agency (approved by Government) or by a private homemaker (chosen by client/family) | Spouse, adult child or parent of a person eligible for services under the Long Term Care Program | Client has been determined eligible, through the Long Tern Care Assessment process, for services under the Long Term Care Program | Client/family responsible for costs of services. Financial assistance provided by Government for those who are unable to pay full costs. Client contribution determined by means of financial assessment. | Demand is relatively high | Respite services are generally contracted from approved Home Support Agencies or are provided by private homemakers chosen by client/family |
| Facility- based | Respite stays of up to 30 days at a time, twice per year, in dedicated nursing home beds | Spouse, adult child or parent of a person with long term care needs | New Brunswick Resident with long-term care needs | \$28/day is client share of total cost of \$115/day | The % of utilization of Nursing Home Relief Care beds is approximately 70% | Most relief care beds are in nursing homes; some are located in special care homes. |
| Day programs | Seniors can participate in activities provided by Adult Day Care | Caregiver of seniors and adults receiving services | Client has been determined eligible, through the Long Term | Seniors pay up to \$7 per day, depending on their ability to pay. | Most services are functioning at full capacity | Vocational day programs for the disabled considered a form of family |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|---|--|--|--|---|--------------------|--|
| | Centres; Adults with disabilities can access ADAPT centres (formerly sheltered workshops) | under the Long Term Care Program | Care Assessment process, for services under the Long Term Care Program | There is generally no cost paid by adults with disabilities. | | respite |
| Palliative Care | Respite hours may be extended for palliative care. | | | | | |
| Disabled | Services under the Long Term Care Program are available to both Seniors and Adults with Disabilities. Adults with disabilities can access ADAPT centres (formerly sheltered workshops) | Family caregivers of disabled adults. | | There is generally no cost paid by adults with disabilities for day programs. | | Vocational day programs for the disabled considered a form of family respite |
| Children (under 19 years of age) | In-home respite: short-term is 4-6 hours/week; daily relief (24 | Family caregivers of children. | Respite services may be purchased by government | Family pays a portion of cost determined by income level. | | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|------------------------|--|--|---|--|----------|----------|
| PROGRAM | DETAILS hours). Maximum of 4 days/month for 11 months for daily and weekend relief; extended relief care up to 14 days/year. | PROFILE | CRITERIA for client depending on need and income level | \$5/hour supplement over family's basic cost; \$50/day for 24 hours or \$75/day for children with enhanced needs; \$100 - \$150/weekend depending on child's needs; \$350-\$525/week | DEMAND | FEATURES |
| | | | | for extended relief care. | | |
| Rural and remote areas | Same programs as rest of province | | | | | |
| Mental health | Services under the Long Term Care Program are available to Seniors and Adults with Disabilities with unmet care needs, regardless of their medical | Generally, clients under the Long Term Care Program have moderate or severe functional limitations resulting from physical | | | | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|---------|------------|--|-------------|--------------|----------|----------|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | diagnosis. | disabilities, intellectual deficits and/or mental illnesses. | | | | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|--------------------------|---|--|--|--------------------------------------|--------------|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| 1. Home Care Services | 1. Home care support worker provides respite. Number of hours per week depends on needs assessment to a maximum of 8 hours/week. Home care support workers can be hired through "chèque-emploiservice" (not-forprofit community-based associations) or by the CLSC [Centre local de services communautaires - Local Community Service Centre – publicly funded]. Respite provided by CLSC home care support workers or workers from agencies. | 1.Caregivers: Elderly spouses, middle-aged children or parents of care recipients. | 1. Case worker assesses need and ability to pay. Income assessment includes income and assets. | User contributes according to means. | High demand. | Respite from inhome services can be increased if combined with other services (e.g. combined with bathing assistance). |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|---|--|---|--|--|--------------------|---|
| I I IOONAW | DETAILO | INOTILL | JATILA | JOLIN | PENAME | ILATORES |
| 2. Palliative Care (CLSC René-Cassin Home Care service). | 2. Respite hours may be increased to a maximum of 28 hours/week. | 2.Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | 2. Patient must be declared a palliative care patient (Has 3 months to live). | 2. No cost. | 2. Low demand. | |
| Volunteer Department | Provides respite through friendly visits, shopping and transportation services. | Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | Caregiver providing care for a care recipient who is frail, homebound or isolated. | No cost. | High demand. | |
| Day Program Caregiver Support Centre: Day Program (Drop-In Center at the CLSC René- Cassin). | Respite time may be booked 24 hours in advance. Respite may start anytime during opening hours: Mon. Wed. Thurs. (11:30am-4:00pm), Tues. (9:30am – 4:00pm), Fri. (10:30am – 3:00pm). | Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | Care-receiver must be autonomous for toileting themselves. Cannot have abusive behavioural problems. | \$7 Drop-In + (taxi \$6/each way if needed). Determined on a sliding scale. No one is refused. | Medium demand | Flexibility in number of hours, starting time and day chosen. Short period of advance booking. An intensive program can be provided (five sessions/week |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|--|---|---|--|--|---|---|
| PROGRAM | DETAILS | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| | | | | | | for 4 weeks). Transportation provided if needed. |
| Other supports for caregivers: Caregiver Support Centre: CLSC René- Cassin Caregiver support programs. | 1. Foyer program: Workshops, support groups, information, education and prevention seminars, (program largely run by volunteers and students under professional supervision). | 1.Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | 1. Be a caregiver to an adult or elderly person. | 1. Support groups: \$2/session. Sliding scale applicable. Other programs have no cost. | 1. Workshops and information seminars: high demand. Support group: medium demand. | 1. Objectives are education, prevention, information and empowerment. |
| | 2. Counselling for caregivers. 8-10 sessions of individual or couples counselling focussing on caregiving issues (coping skills, stress etc.) | 2.Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | 2. Be a caregiver to an adult or elderly person. | 2. No cost. | 2. High demand. | 2. Individual support counselling. |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|---|--|---|--|--|--|---|
| | provided by professional social worker. | | | | | |
| Caregiver Support Centre: C.L.S.C. René- Cassin In Home "stimulation" programs. | Volunteer or student visits home to spend stimulating time with the carerecipient which can provide respite for the caregiver (2 hours per week for 8-10 weeks). | Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | Caregiver caring for a person who is home-bound, frail or isolated. | No cost. | High demand. There is a waitlist for this program. | Services provided at home. Can be a form of respite for the caregiver. |
| 1. Public facility-based respite. | 1. Patient may be placed in long-term care for a period of up to 8 weeks to provide respite for the family. | 1.Caregivers: Elderly spouses, middle-aged children or parents of care- recipients. | 1. Care recipient cannot be medically unstable. Case manager and medical assessment. | 1.\$8/day 48 hours worth of medication can be provided by program but after 48 hours medication is provided by the establishment. | 1. High demand (not enough beds available in the territory). | Caregiver must sign a commitment to take home their care recipient once the respite period is over. |
| 2. Day Centre | 2. Respite time is | 2.Caregivers: | 2. Case worker | 2. Depends on | 2. High demand. | Provides one |

QUEBEC: Institute of Social Gerontology of Quebec – CLSC René-Cassin, Montreal

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|------------------|---------------------|-------------|-------------------|------------------|----------|-----------------|
| PROGRAM | DETAILS | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| | | | | | | |
| and Day | offered on specific | Elderly | assesses need | facility. Varies | | meal and |
| Hospital. | days of the week | spouses, | and makes the | from \$8- | | transportation. |
| (Short-term | during opening | middle-aged | referral directly | \$10/visit. | | |
| public facility- | hours. Maximum 2 | children or | to the facility. | | | |
| based | days per week. | parents of | Eligibility | | | |
| respite). | | care- | dependant on | | | |
| | | recipients. | individual | | | |
| | | | facility. | | | |
| *CLSC. may | | | | | | |
| have access | | | | | | |
| to other | | | | | | |
| resources for | | | | | | |
| respite for | | | | | | |
| their clients. | | | | | | |

Note: The CLSC considers other options for respite as including the Day Center, or day hospital (including the Drop-In Center at the CLSC René-Cassin).

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|---------------------|--|--|--|--|--------------------|--|
| In-home services | Respite Services Include: Community Care Access Centre: Nursing services Personal support and homemaking services Community Support Services (accredited not-for-profit and private sector agencies) Caregiver support service (respite) for all client types | Elderly spouses; middle-aged children of frail/elderly; Parents of high needs children | Determined through Community Care Access Centre case manager Determined through Community Support Services intake | No cost to user Some services no cost 'Brokered' programs match a worker with a client and the worker is paid directly by the client. Some volunteer respite services | | No means test or income threshold; all those with OHIP (Ontario Health Insurance Plan) covered; Needs assessment determines level of service within existing legislation, regulation and policy and existing financial resources Community Support Services |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|----------|-------------------------|------------------------|-------------------------|-------------------|-----------------|-------------------------|
| PROGRAM | | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | | | | agencies set |
| | | | | | | their own |
| | | | | | | criteria for |
| | | | | | | eligibility |
| | | | | | | according to |
| | | | | | | the type of |
| | | | | | | service |
| | | | | | | offered |
| Facilty- | Long-Term Care | Caregivers of | Determined by | Daily per diem of | Varies | Same as |
| based | Facility based, in | middle-aged to | the CCAC. The | \$30.90 for | across the | long-stay |
| respite | nursing homes, | elderly with | same eligibility | accommodation | province, | long-term |
| | municipal or charitable | multiple | requirements | | would | care facility |
| | homes for the aged. | diagnosis and | as for | | estimate a | residents. |
| | | varying levels of care | admission to a | | medium | Users are |
| | | | long-term care | | level of demand | encouraged |
| | | requirements | facility: - At least 18 | | demand | to join in recreational |
| | | | years old; | | | programs |
| | | | - An insured | | | offered in the |
| | | | person under | | | facilities. |
| | | | the Health | | | lacinties. |
| | | | Insurance Act; | | | Programs |
| | | | - Applicant | | | offered in the |
| | | | meets one of | | | community |
| | | | the following: | | | remain in |
| | | | -Requires | | | effect, i.e. |
| | | | that nursing | | | restorative |
| | | | care be | | | care, OT/PT. |
| | | | available on- | | | In situations |
| | | | site 24-hrs a | | | where the |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|---------|-----------------|---------|-----------------|--------------|----------|---------------|
| PROGRAM | | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | day; | | | user is a |
| | | | -Requires | | | client of an |
| | | | assistance | | | Adult Day |
| | | | each day | | | Program, |
| | | | with | | | where |
| | | | activities of | | | possible, |
| | | | daily living; | | | ADP program |
| | | | - Requires, | | | attendance is |
| | | | at frequent | | | encouraged. |
| | | | intervals, | | | |
| | | | on-site | | | |
| | | | supervision | | | |
| | | | or on-site | | | |
| | | | monitoring | | | |
| | | | to ensure | | | |
| | | | safety or | | | |
| | | | well being; | | | |
| | | | - Is at risk of | | | |
| | | | harm if | | | |
| | | | living in own | | | |
| | | | residence; | | | |
| | | | - At risk of | | | |
| | | | suffering | | | |
| | | | harm from | | | |
| | | | environment | | | |
| | | | ; or | | | |
| | | | - May harm | | | |
| | | | someone is | | | |
| | | | living in own | | | |
| | | | residence. | | | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|------------|--|----------------|-----------------|-----------------|----------|----------------|
| PROGRAM | | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | - Applicants | | | |
| | | | needs can be | | | |
| | | | met in a long- | | | |
| | | | term care | | | |
| | | | facility; and | | | |
| | | | needs cannot | | | |
| | | | be met in | | | |
| | | | community | | | |
| Day | Community Support | Caregivers of: | Community | User Fees | | - Client often |
| programs | Services: | frail elderly; | Support | | | uses Adult |
| | Adult Day Programs | individuals | Services | | | Day |
| | · Wheels-to- | with Alzheimer | agency or | | | Programs so |
| | Meals <u>/</u> Congregate | disease and | Community | | | family |
| | Dining | other | Care Access | | | members can |
| | · Alzheimer/dementia | progressive | Centre may | | | continue |
| | overnight service | cognitive | determine Adult | | | working |
| | Programs often funded | disorders and | Day Program | | | - Access to |
| | by voluntary sector; | dementia; | eligibility | | | Adult Day |
| | may have some | persons with | | | | Programs is |
| | government support. | an acquired | | | | either |
| | | brain injury | | | | through the |
| | | | | | | CCAC or |
| | | | | | | directly |
| | | | | | | through the |
| | | | | | | CSS agency |
| Palliative | Community Care | Caregivers of | Determined | No cost to user | | Same as |
| care | Access Centres | those dying | through CCAC | | | CCAC |
| | | with a life- | case manager | | | services |
| | | threatening | | | | above |
| | | illness | | | | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|----------|---|--|-------------------------------------|-----------------|----------|--------------------------------------|
| PROGRAM | | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | Community Support Services Volunteer-based inhome hospice care (usually funded through charitable donations; may have some government support) | | Determined through CSS intake | No cost to user | | |
| Children | Community Care Access Centres Services are available to assist families with medically fragile, technology dependent children and/or children with complex care needs | Caregivers of medically fragile, technology dependent children and/or children with complex care | Determined by CCAC case manager | No cost to user | | Same as CCAC services above |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|---|--|-----------------|-------------------------|--------------------------|--------------------|---------------------|
| Rural and remote areas | Same programs as rest of province | | | | | |
| Mental health | No specific respite programs | | | | | |
| Support groups for family caregivers | Alzheimer Society Public Education Coordinators Caregiver support groups available through local chapters (largely funded by charitable donations) | | | User fees may be charged | | |
| Other services for caregivers | Community Support Services Caregiving training, information and education services and therapeutic counselling/support | | | | | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|---------------------|--|--|--|-----------------|----------|----------|
| PROGRAM | | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| In-home services | In addition to assessed hours of direct Home Care services, several hours of "family relief" per week possible, depending on need (upper limits for Home Care can be exceeded for palliative care, waiting placement, family crisis or other short term need). Longer term respite such as two week vacation relief usually provided in facility due to limitations of availability of workers in the community. | Elderly spouses; middle-aged children of elderly; spouses and family members of adults, parents of children. | Manitobans of all ages are eligible for Home Care when they require health services or assistance with activities of daily living so that they can remain in their homes for as long as possible. They must require more assistance than that available from existing supports and community resources. There is no income and assets assessment to determine eligibility. | No cost to user | High | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|-----------|--------------------------------|-------------|---------------------|----------------|---------------|---------------|
| PROGRAM | | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| Facility- | Personal Care Home – | Elderly | The individual | \$26.30/day | High for | |
| based | usually planned and | spouses; | must meet the | (this is | personal care | |
| respite | reserved in advance. | middle-aged | eligibility for the | minimum rate | home. | |
| | Usually no more than | children of | personal care | for personal | Low demand | |
| | two weeks at a time. | elderly; | home program. | care homes). | for hospital | |
| | No maximum number | spouses | This includes the | No cost for | respite. | |
| | of stays per year – | and family | Manitoba | hospital stay. | | |
| | number of stays | members of | residency | | | |
| | depends on | adults, | requirements. | | | |
| | assessment and | parents of | Access to respite | | | |
| | available resources. | children. | in hospital is | | | |
| | Arrangements can | | through | | | |
| | usually be made for an | | physician. | | | |
| | emergency respite admission in | | | | | |
| | circumstances such as | | | | | |
| | a sudden family | | | | | |
| | illness. | | | | | |
| | In-hospital respite is | | | | | |
| | more rarely used and | | | | | |
| | would be more likely in | | | | | |
| | rural Manitoba. | | | | | |
| Adult Day | Most day programs | Elderly | The client must | \$8.60/day to | High | Day |
| programs | offered through | spouses; | be eligible for the | cover meals | | programs |
| _ | personal care homes. | middle-aged | Home Care | | | largely |
| | Most programs for full | children of | program. | | | offered |
| | day and provide a | elderly; | Individuals | | | through |
| | meal. Some | spouses | whose needs for | | | personal care |
| ĺ | community-based | and family | health | | | homes |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|--------------------|--|---|---|-----------------|--------------------|-----------------------|
| PROGRAM | groups are sponsors of day programs. | members of adults, parents of children. | maintenance, social stimulation and peer group activities, can best be met by participation in an Adult Day Care program shall be referred to the appropriate Adult Day Care sponsor following assessment by the Home Care Case Coordinator. An equally important objective would be to provide essential respite for caregivers. | USEK | DEMAND | (publicly- funded) |
| Palliative care | Number of hours of in- home respite may be increased | | The client must be eligible for the Regional Health Authority Palliative Care program. | No cost to user | | |
| Disabled | Covered under In- home and facility | | | No cost to user | | |

| RESPITE | PROGRAM DETAILS | USER | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|------------------------|--|----------------------------------|---|----------------------|----------|----------|
| PROGRAM | | PROFILE | CRITERIA | USER | DEMAND | FEATURES |
| | based details | | | | | |
| Children | Home Care funded by MB Health may provide in-home nurse for respite; MB Family Services and Housing provides respite for families of children with long term disabilities including a developmental delay. | Mostly parents of children | Children would meet the eligibility criteria for Home Care and/or the eligibility criteria for Children's Special Services, FS & H. | No cost to the user. | | |
| Rural and remote areas | Same programs as rest of province. No specific respite | | | | | |
| health | programs | | | | | |

Note: Definitions used in Manitoba:

Family Relief

Family relief is care provided at home as a Home Care service for short periods during the week for the purpose of supporting the family environment by providing relief to family/informal caregivers to permit them time to shop, attend to business or to obtain needed rest.

Respite Care

Respite care is care provided for weekend or extended periods (e.g. 2 week vacation) for family/informal caregivers who regularly provide extensive care.

Respite care is based on a Home Care assessment and may be provided:

- 1. through Home Care as care for the client at home
- 2. through a temporary stay for the client in a respite bed in a personal care home; through a stay in hospital.

SASKATCHEWAN

| respite program | program details | user profile | eligibility criteria | cost to user | level of demand | special features |
|-------------------------------|--|---|--|---|--|---|
| p. og. a | | | 01110110 | | | |
| In-home services | Usually 2-3 hours a day for 2-3 times a week (homemaker in home). Must be planned ahead. Extra hours possible in exceptional cases. Access depends on availability of staff and resources in the district. If 24-hour care is needed, respite is provided through facility-based respite | Mostly senior caregivers (spouses of elderly client) | Need assessed by regional health authority/ Low-income clients eligible for some subsidy. | \$6.10/hour up to a maximum monthly expenditure of from \$61/month to \$366/month (depending on income) after which costs are covered by the program. | Varies | |
| Facility- based respite | Respite beds are available in Special Care Homes (publicly funded). Lighter care is provided in personal care homes (not publicly funded). Respite period in special care home is usually 30-60 days but may be | Mostly senior caregivers (spouses of elderly client) | Need assessed by regional health authority | Lowest rate is approximately \$800/month | High demand with wait lists in larger communities | Respite for longer than 60-day period indicates need for patient to be placed in a special care home. |

SASKATCHEWAN

| respite | program details | user profile | eligibility criteria | cost to user | level of | special |
|------------------------|--|--|---|--|----------|----------|
| program | extended. | | Criteria | | demand | features |
| Day programs | Provided in Special Care Homes (publicly funded). Clients usually participate from 1-3 days/week. | Mostly senior caregivers (spouses of elderly client) | Need assessed by regional health authority | \$5.25/day plus transportation cost if any | | |
| Palliative care | Hours may be extended for palliative care | | | | | |
| Disabled | Covered by home care program (as above) | | Need assessed by regional health authority | | | |
| Children | Covered by home care program | | | | | |
| Rural and remote areas | Same as for rest of province | | | | | |
| Mental health | Most persons living with mental health conditions live in supportive housing or group homes. Relatively little home care provided by families. | | | | | |

ALBERTA

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|-------------------------------|---|--|---|---|----------|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | | | | |
| In-home services | Home care worker in home. Maximum number of hours per month is determined by \$3000/month cap. | All family caregivers (providing care for Albertans of all ages) | Assessment by regional health authority. No income or asset means test. | \$5/hour to a maximum of \$300/month based on a sliding scale according to income. Ceiling for all home care services is \$3000 per month (under review). This ceiling can be exceeded for palliative care clients. | | All ages and diagnoses covered by home care program. New "Aging in Place" policy being developed. Alberta has strong Alzheimers programs (voluntary sector with some public funding). |
| Facility- based respite | Bed in long-term care facility usually for two-week period. Length of time can be up to one month or longer, depending on | | Determined by needs assessment | Provincial accommodation charges are: \$28.22/day standard room; \$29.93/day shared room; \$32.60/day private room | | Long-term care facilities a mix of public, voluntary and for-profit |

ALBERTA

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|--------------------|---|---------|-------------|---|----------|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | assessed need. Requires advance reservation | | | If these charges pose a significant financial difficulty, health authorities have hardship policies in place. | | |
| Day programs | Offered by both publicly-funded long-term care facilities and the voluntary sector e.g. Alzheimer Society offers many day programs. | | | Minimal cost for meal and transportation costs to and from home. | | Some day programs offered during the evening to allow family members evening time off (e.g. Calgary Alzheimers program Thursday evening program from 6 pm – 10 pm) |
| Palliative care | The Home Care Regulation was revised to exempt palliative care clients from the \$3,000 limit for home care services. | | | Ceiling of \$3000/month for home care services can be exceeded for palliative care clients. | | |
| Disabled | Provision of home care service is | | | | | |

ALBERTA

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|------------------------|---|---------------------|-------------------------|--------------|--------------------|--|
| | based on assessed need. | | | | | |
| Children | Provision of home care service is based on assessed need. | Parents of children | | | | |
| Rural and remote areas | Provision of home care service is based on assessed need. | | | | | Province wide Health Link (telehealth) is now available throughout Alberta to provide information to caregivers and can refer to counselling services. |
| Mental health | Provision of home care service is based on assessed need. | | | | | |

Note: Under the provincial home care policy, Alberta defines a "family member" as including the immediate family of the individual requiring care (parents, children, siblings, grandparents, grandchildren including those related through marriage or common-law), trustees or guardians, or relatives normally residing with the individual.

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|-------------------------------|---|--|--|--|--------------------|---|
| In-home services | Four-hour periods or weekend breaks | Elderly spouses; middle- aged children of elderly; spouses and family of younger adults | Patient must meet Home and Community Care (HCC) eligibility criteria e.g. citizenship, residency age i.e. must be 19 years of age, and must consent to a financial assessment which is based on income not assets. | Sliding scale depending on client's financial assessment. Payment ranges from \$0 to the actual full cost of care. | High | Most clients are low income. All diagnoses are eligible for home care. Respite services now under review. |
| Facility- based respite | Up to 30 days/year with additional time if assessed as needed and approved as exception by regional health authority. | As above | As above | Client pays the respite rate of \$27.10/day (equivalent to OAS-GIS). This is equivalent of lowest residential care rate. | high | |
| Day programs | Half or full days | Client attends | As above | Maximum cost is \$6.00/day, which | Medium | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|--------------------|--|---|--|--|---|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | program, which gives caregiver time off | | is the nominal daily fee to each client to assist with the cost of crafts, transportation (if provided) and meals. | | |
| Palliative care | Respite hours may be extended for palliative care | As above for in-home services | As above | | High | |
| Disabled | Respite services for persons with disabilities is not differentiated as a separate program. Disabled clients access the same services of inhome or facility based respite. | As above for in-home services | As above | | High | |
| Children | 1. In home: Nursing Support Services provides nursing support from 4- 56 hours/week in home care | Parents and family caregivers of children with complex health | 1. Nursing assessment determines if the care needs of the child require nursing support in the | 1. None. It is important to note that there are huge costs to families that have child with complex health | 1. High levels of demand as hospitals are discharging children earlier, with more complex needs | 1. Very individualized services that focus on maximizing the child's quality of life and |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|---------|---------------------|--------------|-------------------|------------------------------------|-------------------|-------------------|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | depending on | needs | home when the | needs. See note | and | integration into |
| | the care needs | between the | • | below. | interventions | the community |
| | of the child | ages of 0-19 | available | | still underway. | |
| | | yrs | | | | |
| | 2. Facility-based | | | | | |
| | respite: | | 2. Require | 2. Often covered | 2. Medium – | 2. Limited |
| | Some family or | | respite due to | by respite funds | most families | resource that |
| | 2-4 bed homes | | health need – | family may pay | want to be with | can meet the |
| | provide respite. | | usually referred | some. | their child. | individualized |
| | Canuck Place in | | from another | | Many children | needs of the |
| | Vancouver | | program and fall | | DO NOT want to | child and family. |
| | (residential | | under the | | be away from | |
| | palliative care | | criteria of that | | their parents for | |
| | hospice funded | | program. | | long periods. | |
| | largely by | | | | | |
| | charitable | | | | | |
| | donations) | | | | | |
| | provides | | | | | |
| | palliative respite. | | | | | |
| | 3. School and | | | | | |
| | child care | | | | 3. High – all | |
| | programs: | | 3. same Nursing | | children want to | |
| | Nursing Support | 3. School | Support | 3. None. Nursing | participate in | |
| | Services | and child | Services criteria | consult/care | activities with | |
| | provides | care | | covered by | their peers. | |
| | delegated and | programs | | Nursing Support | These age | |
| | direct care to | can provide | | Services. | appropriate | |
| | enable children | respite for | | Teaching assistant is | activities are | |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|---------|---|--|--|--|---|--|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | to attend school and childcare programs Maximum: a) School: 35 hr/week b) Childcare: 20 hrs week | parents and family caregivers of children | | covered by the school district. Child care work is paid by parent's child care fees and maybe supplements due to the one on one care by the Supportive Child Care program. | essential to the well being of the child. | |
| | 4. Palliative care – children: Nursing Support Services in home and community Canuck Place (residential palliative care hospice for children funded largely by charitable donations) offers 20 days per year of respite to children with limiting illness. | 4. Parents and family caregivers of children with life- limiting illness | 4. Child must have life-limiting illness | 4. No cost to user | 4. High. Nursing Support Services has increased demand for supports as more families choose to have the children die at home. | 4. Nursing Support Services provides comprehensive consultation in the community with other service providers. |

| RESPITE | PROGRAM | USER | ELIGIBILITY | COST TO USER | LEVEL OF | SPECIAL |
|-----------|---------------|---------|-------------|--------------|----------|----------|
| PROGRAM | DETAILS | PROFILE | CRITERIA | | DEMAND | FEATURES |
| | | | | | | |
| Rural and | Same programs | | | | | |
| remote | as rest of | | | | | |
| areas | province | | | | | |
| Mental | Covered by | | | | | |
| health | regular home- | | | | | |
| | care program | | | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|-------------------------------|--|---|---|--|---|---|
| | | | | | | |
| In-home services | Homemaker will come for as many hours as needed. Number of hours determined by assessed need and available resources. Not intended to free caregiver to go to work. | Spouses of chronic care adults, parents, spouses with young children, parents of children and teens. Caregivers of clients with early-onset multiple sclerosis or Alzheimers. | All ages and diagnoses. Case manager assesses need. | No cost to user (no means test). | | Strong emphasis on keeping client in the community. Only 60% of community care users are seniors because of relatively young population in Yukon. |
| Facility- based respite | Respite care in all residential facilities and in all program areas. Limited only by availability of beds. | Caregivers of those receiving: dementia care, extended care, intermediate care, personal care – all ages. | | \$18/day for regular care and \$21/day for more intensive care | | |
| Day programs | Day programs in three largest communities | · · | Patient has physical or cognitive impairment | \$6/day to cover meal cost | High demand has been met by recent program expansion. | Recent program expansion has eliminated wait lists |
| Palliative | Respite hours may | | | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|------------------------------------|--|--------------|-------------------------|-----------------|--------------------|---|
| care | be extended for palliative care. Also available in facilities | | | | | |
| Disabled Children | Covered by programs described above. Facility-based respite beds only in Whitehorse. | | | | | |
| Rural and remote areas | Same program as rest of Yukon. Clients have to go to nearest large community for facility-based respite. | | | | | Outreach teams visit remote communities. |
| Mental health | Covered by programs described above. Facility-based respite beds only in Whitehorse. | | | | | |
| First Nations and Inuit population | see First Nations and Inuit Health Branch, Health Canada | | | | | 25% of Yukon population is First Nations; very few Inuit |

NORTHWEST TERRITORIES

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|-------------------------------|---|--|---|--|--------------------|---|
| In-home services | Home support worker through home care program for a few hours according to assessed need and available resources | Elderly spouses; middle-aged children of elderly; spouses and family of younger adults, and families of children with disabilities | Assessment by regional health and social services. All ages and diagnoses. Level of service depends on resources of regional health and social services authority. No assessment for income and assets. | No cost | Medium | Small First Nations and Inuit communities covered through Health Canada FNIHB funds added to NWT funding to develop an integrated system. First Nations and Inuit represent close to 50% of population. All services provided by public agencies (no private agencies operate in NWT) |
| Facility- based respite | One respite bed in each of the 8 long-term care facilities in NWT if available. One respite bed in each group home for respite. Average stay is 1-90 days with no | Caregivers of seniors, adults and children with special needs. | NWT health care card, assessed need. | \$0- 300 for residents under 65 years of age. \$0-712 for residents over 64 years of age | Low | |

NORTHWEST TERRITORIES

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | LEVEL OF DEMAND | SPECIAL FEATURES |
|--------------------|---|---|--------------------------------|-----------------|--------------------|--|
| | maximum time limit. | | | | | |
| Day programs | Some long-term care facilities may provide a drop-in day program. | Caregivers of seniors living with families. | Based on need and availability | Varies. | Medium | |
| Palliative care | Respite hours may be extended for palliative care | | | | | |
| Disabled | Respite available through the home care programs. Some programming provided by voluntary organizations (e.g.Council for Persons with Disabilities) with some government funding | Available for caregivers caring for family members of all ages through the home care programs based on assessed need. | | | | Other programs include a early intervention program for children with disabilities through a nongovernment agency. |
| Children | Covered by same programs as adults. Some respite provided through the health and social services authority specifically for foster children. Option available for respite through a Voluntary | Parents of children. Foster parents. | Case specific | No cost | Medium | |

NORTHWEST TERRITORIES

| RESPITE | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY | COST TO | LEVEL OF | SPECIAL |
|------------------------|---|---|-------------------------|---------|----------|----------|
| PROGRAM | | | CRITERIA | USER | DEMAND | FEATURES |
| | Support Agreement. | | | | | |
| Rural and remote areas | Same programs throughout NWT | | | | | |
| Mental health | Home care programs provide some mental health clients' families with respite based on assessed need and availability. | Families with high needs mental health issues | Based on assessed needs | No cost | Medium | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | TO USER | level of demand | SPECIAL FEATURES |
|---------------------|--|----------------------------|--|------------|-----------------|--|
| In-home services | No formal programs developed yet | Family caregivers | Assessed need, by social worker (homemaker services) or home care nurse (other respite services) | No cost | High | Homemaker services (housekeeping, inhome meal preparation, etc.) available in all communities. Respite services funded by Health Canada (First Nations and Inuit Health Branch) still being developed. Training is being delivered in 17 of the 25 Nunavut communities for informal caregivers. Extended family system and community volunteers may provide informal respite services. |
| Facility- based | 1. Elder care centre with nursing services | 1. Primarily caregivers of | Assessment by admissions | No cost | High | Services are offered to those whose |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO | level of demand | SPECIAL FEATURES |
|--------------------|---|--|---|------------|-----------------|---|
| respite | in Iqaluit; one hospice/elders group living centre in Baker Lake (access to off-site nurse) and one elders' home in Arviat. The Baker Lake Hospice has one bed dedicated to respite services. In Iqaluit/Arviat, no formal respite services developed yet, but facilities are used frequently for respite, where space permits. 2. Adult group homes, Iqaluit and Rankin Inlet – limited respite care. | 2. Primarily caregivers of developmentally delayed adults | Committees Program eliente | USER | | needs are highest, if patient can be safely accommodated with the limited supports available. |
| Day programs | Taparti Centre, Rankin Inlet Akkausisarvik – mental | Cargivers of developmentally delayed adults Caregivers of | Program clients are mostly residents of adult group homes; others | No cost | | |
| | health day programs | severely and | as self-identified | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|------------------------|---|---|-------------------------|--------------------|--------------------|--|
| | (life skills, coping etc.) | moderately mentally ill | and self-referred | | | |
| Disabled | No formal respite programs developed yet | | | | | |
| Children | Childrens' group homes, Iqaluit, Rankin Inlet and Cambridge Bay – all provide limited respite services. Chesterfield Inlet long term care | Families of developmentally delayed children Families of severely delayed children | Clinical assessment | No cost | High | Programs for children and youth are a priority for development. The population of Nunavut is relatively young and has problems such as substance use and high suicide rates. |
| Rural and remote areas | Most of Nunavut population lives in 25 communities; 13 of these communities have home care nurses. People with high care needs have gone to Iqaluit or were sent south for care. As home care services and supports to informal caregivers improve, focus is on | | | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|--------------------|--|--|-------------------------------------|--------------------|-----------------|---|
| | service as close to home as possible. | | | | | |
| Mental health | Akkausisarvik transitional facility in Iqaluit, provides limited respite opportunities for mental health clients. | Family caregivers of severely and moderately mentally ill | Established by admissions committee | No cost | High | Mental health programs a priority for program development (family violence, psychology services, substances, suicide) |

Services in Yukon are also described as an example of the programs being developed

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|---------------------|---|--|----------------------------|------------------------|-----------------|--|
| In-home services | Availability will depend on community-designed program and community resources. An estimated 50% of communities may offer in-home respite care. Yukon: most First Nations communities have identified caregiver respite as a need. Only one of 14 First Nations communities currently offering it. First Nations home support workers currently being trained. | Caregivers of disabled adults; caregivers of seniors | Case manager assessed need | No direct cost to user | | In-home respite defined as an essential service element of the Home and Community Care Program. The FNIHB Home and Community Care Program builds on the Department of Indian and Northern Affairs Adult Care Program, which supports in-home, facility-based and foster care for the elderly, disabled or others with needs (respite is not a component of the DIAND program). Home and Community Care Program announced in 1999 Budget and still being developed. 71% of communities now have access to services, covering 82% of eligible |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|--------------------|-----------------|-----------------|-------------------------|--------------------|-----------------|--|
| | | | | | | population. Resources allocated to communities based partly on hospital discharge rates and need for follow-up home care. In many regions, services will be linked with provincial health authorities/ and integrated with territorial services. Community service plans have to meet program standards and policy requirements. All ages and diagnoses covered. Palliative care not a formal part of the Home and Community Care Program. FNIHB currently does not have the mandate to deliver palliative care services As communities develop services, FNIHB will act as funder and evaluator and will monitor services delivered by communities. |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|-------------------------------|--|-----------------|-------------------------|---------------------------------|-----------------|---|
| | | | | | | Yukon: high degree of integration of Yukon government health services and FNIHB-funded services. |
| Facility- based respite | Very few communities offer this. One reason is health decline when client leaves home community and enters unfamiliar culture. Preference is to offer inhome care when possible. There are 30 | | | No direct cost to user | | Defined as a supportive service element rather than an essential element of the Home and Community Care Program. |
| | First Nations personal care homes on large reserves. Yukon: FN clients have access to respite beds | | | | | |
| | in Yukon government long-term facilities. | | | | | |
| Day programs | Very few communities offer them (less than 10%) | | | | | Day programs defined as a supportive service element rather than an essential element of the Home and Community Care Program. |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|------------------------|--|-----------------|-------------------------|--------------------|-----------------|--|
| Palliative care | Formal palliative care program not yet developed | | | | | FNIHB does not currently have a mandate to provide palliative care. Palliative care defined as a supportive service element rather than an essential element of the Home and Community Care Program. |
| Disabled | | | | | | |
| Children | | | | | | |
| Rural and remote areas | | | | | | Program funding provided by FNIHB, for example home and community care, provides additional funding for remote and isolated communities. |
| Mental | No specific respite | | | | | |
| health | programs | | | | | |

| RESPITE | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY | COST TO USER | level of | SPECIAL |
|---------------------|--|---|---|--|----------|---|
| PROGRAM | | | CRITERIA | | demand | FEATURES |
| General | | | Patient for whom family caregiver is providing care must be a client who is eligible for the requested services under the programs administered by VAC. | VAC will consider the services available from provincial/territorial programs and the client's eligibility status in determining the extent of funding provided. VAC normally pays for the full cost of approved respite services with the exception of care in a long-term care facility where the client may be required to contribute toward the cost of accommodation and meals. | | |
| In-home services | Housekeeping; grounds maintenance; personal care; time off for a few hours, a day, or overnight. | Elderly spouse; middle-age family member with other family responsibilities (average age of | Need assessed by a case manager. Needs must be related to a disability for which a | VAC normally provides a contribution to cover the cost of the services required based on the needs assessment. | | Program is designed to avert caregiver burnout or crisis before it happens. |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|-------------------------------|---|--|--|--------------|-----------------|---|
| | | veterans is 79). | pension has | | | VAC |
| | | Young parents with children (spouses of younger clients). | been granted by VAC, or be a veteran of World War I, World War II, or Korea, and income qualified. | | | resources are intended to supplement and complement services available in client's community. |
| Facility- based respite | Available under care plan. Subject to annual limit of 59 days for all respite services. | Elderly spouse; middle-age family member with other family responsibilities (average age of veterans is 79). Young parents with children (spouses of younger clients). | Client must have a need and be eligible for VAC programs based on a disability for which a pension has been granted, or meets military service requirements. | | | |
| Day programs | May be available especially in cases of client dementia | Elderly spouse; middle-age family member with other family | Need assessed by a case manager. Needs must be related to a | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|--------------------|---|--|---|--------------|-----------------|---------------------|
| | | responsibilities (average age of veterans is 79). Young parents with children (spouses of younger clients). | disability for which a pension has been granted by VAC, or be a veteran of World War I, World War II, or Korea, and income qualified. | | | |
| Palliative care | Respite hours may be extended during palliative care. | Elderly spouse; middle-age family member with other family responsibilities (average age of veterans is 79). Young parents with children (spouses of younger clients). | Need assessed by a case manager. Needs must be related to a disability for which a pension has been granted by VAC, or be a veteran of World War I, World War II, or Korea, and income qualified or meet military service | | | |

| RESPITE PROGRAM | PROGRAM DETAILS | USER PROFILE | ELIGIBILITY CRITERIA | COST TO USER | level of demand | SPECIAL FEATURES |
|------------------------|--|--------------|---|--------------|-----------------|---------------------|
| | | | requirements during specific periods. | | | |
| Disabled | As above | | | | | |
| Children | Covered under provincial/territorial plans | | | | | |
| Rural and remote areas | Same provisions as other clients | | | | | |
| Mental health | Same provisions as other clients | | | | | |