



## HOME CARE

A background paper to accompany  
***Health Care Renewal in Canada: Accelerating Change***  
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## **Executive Summary**

### **Introduction**

The home health care sector is a growth sector. However, these vital programs have not, until recently, received the attention and funds they need to fulfill their mandates and potential. Though home care programs exist in all Canadian provinces and territories, some are more established than others. The federal government also provides home care to Canadians not covered by provincial health programs. These include members of the Canadian Forces, veterans, members of the RCMP who are appointed to a rank, individuals serving a term of imprisonment in a penitentiary, and First Nations and Inuit living on a First Nations reserve or Inuit settlement.

The 1990s saw considerable growth in the post-acute home care sector, stimulated by a number of demographic factors and policy reform initiatives; these include an aging population, hospital downsizing and shorter lengths of stay, as well as technological and medical advancements that allowed for more care to be provided safely in the home. However, hospital downsizing and shortened lengths of stay have outpaced the development and expansion of home care programs. As a result, family and volunteer caregivers have been shouldering an increasing amount of the need for care.

### **What have governments promised?**

Through their 2003 Accord on Health Care Renewal, the First Ministers targeted home care for an infusion of funds, made it a priority area for reform, and began to establish national standards for short-term acute home care, acute community mental health, and end-of-life care. In addition, the federal government agreed to establish a compassionate care benefit through the Employment Insurance Program and job protection through amendments of the Canada Labour Code.

Although they did not reach consensus on a basket of services in 2003, through the 2004 First Ministers' 10 Year Plan, the Ministers agreed to provide first-dollar coverage by 2006 based on assessed need for the following:

- Short-term acute home care (STAHC) for two-week provision of case management, intravenous medications related to the discharge diagnosis, nursing and personal care;
- Short-term acute community mental health home care for two-week provision of case management and crisis response services; and
- End-of-life care for case management, nursing, palliative-specific pharmaceuticals and personal care at the end-of-life.

The First Ministers also agreed to report annually to their citizens on the progress in implementing home care services, to use comparable indicators and to develop the necessary data infrastructure for these reports.

This report is a review of the activities that have taken place in each of the federal, provincial and territorial jurisdictions in implementing and meeting the elements outlined in the 2003 Accord up to and including the First Ministers' meeting held in September 2004. The information for this report comes from a number of sources:

- review of documents/reports/academic literature;
- survey questionnaire sent to each federal, provincial and territorial jurisdiction regarding their home care services;
- interviews with key informants; and
- website searches.

### **Minimum Basket Of Services – *Promises and Gaps***

Although the First Ministers did not reach consensus on a minimum basket of services for home care programs by September 2003, they did outline the basket of services and time limits for the three program areas in their meeting of September 2004. However, the 2003 Accord and the 2004 plan do not say that all these services need be fully publicly funded for all home care clients. Rather, these agreements provide that there should be first-dollar coverage for short-term acute home care, acute community mental health, and end-of-life care. In the insurance literature, first-dollar coverage means there is no deductible limit that the individual must pay either through private insurance or out of pocket. As a result, first-dollar coverage can mean full public funding with no deductibles or public funding with no deductibles but with user charges/co-payments. Succinctly put, first-dollar coverage does not mean full-dollar coverage. Provincial/territorial programs could charge or continue to charge user fees for home care services in the basket.

The 2003 Accord further suggests that by 2006 the minimum basket of services could include nursing/ professional services, pharmaceuticals and medical equipment/supplies, support for essential personal care needs, and assessment of client needs and case management. The 2004 plan falls somewhat short of the services proposed in 2003. For short-term acute home care and acute community mental health, a two-week maximum limit was placed on services. Regardless of the interpretation of first-dollar coverage, the time limit on services is likely an attempt to limit financial exposure and may be based on the belief that most patients undergoing acute episodes of either a physical or mental nature are cured or stabilized within two weeks. The impact on clients of these services is discussed below.

### **Short-Term Acute Home Care – *Promises, Status, and Gaps***

Acute home care clients comprise anywhere from 17 per cent (Yukon) to 56 per cent (British Columbia) of the home care population, with a Canadian average of 33 per cent. Care provided to short-term clients consists of nursing services (63 per cent), personal support (21 per cent) and other therapies (16 per cent). In contrast, continuing care clients largely require personal support (59 per cent), followed by nursing care (36 per cent).

Poor discharge planning and a shortage of home and community support services have led to emergency room congestion and to patients being cared for longer in hospital than necessary as well as an increase in the use of Alternate Level Care beds.

The provision and public funding of STAHC services mirrors to a large extent general home care services. Some jurisdictions have time limits on how long a client can be provided short-term acute home care services or a maximum dollar limit usually equivalent to the cost of institutional care. All jurisdictions fully fund assessment, case management, and nursing care although some place a time limit on the latter. Rehabilitation therapies, medical equipment and supplies, nutrition, and drugs are less reliably provided and often involve a co-payment.

Neither the 2003 or 2004 First Ministers' agreements is clear whether STAHC is reserved for post-hospital discharge care or if it is also intended to prevent hospitalization for clients experiencing an acute physical/functional episode. The recommendations for first-dollar coverage and a two-week limit on services are probably reasonable given the progress of most acute episodes and the desire of jurisdictions to limit their liability. However, if short-term acute home care is to substitute for hospital care, the basket should focus instead on providing full-dollar coverage for care in the home that would otherwise be provided and fully paid for in hospital. Otherwise, for those clients requiring more than two weeks of service, the STAHC program may represent not just a substitute for hospital care but a de facto reduction in benefits under the *Canada Health Act*. The agreed upon basket specifies assessment, case management, nursing and personal care. Intravenous medication is to be provided only if it relates to the discharge diagnosis, implying it will be available only for post-hospital care. Notably absent from the basket are rehabilitation therapies, which are crucial for certain conditions and procedures such as stroke or hip/knee replacements. Key informants strongly recommend that the basket specifically include rehabilitation therapies as a component of short-term acute home care, and any other services that would have been fully funded if provided in an acute care facility.

### **Acute Community Mental Health – *Promises, Status and Gaps***

The mental health sector, especially its community-based component, has been disproportionately under-funded compared with other sectors. It includes some of the most vulnerable people in our society, many of whom are homeless. Where community mental health services exist, they are typically not delivered through home care programs, but rather through a variety of different sectors and providers operating under a range of government departments. There is also significant variation in services provided across the country with availability limited by financial and human resources. Jurisdictions should identify the specific needs of their populations and determine whether they have the right mix of programs to meet those needs.

Addictions are not mentioned in the 2004 plan as a criterion for acute community mental health services. People with mental illness have much higher rates of addiction and those with an addiction problem have much higher rates of mental illness than the general

population. These individuals are said to have a concurrent disorder. Best practice guidelines suggest an integrated approach to assessment, treatment and support for persons with concurrent disorders.

Given the nature of mental illness and the unique needs of this population, key experts view a focus on acute episodes and a two-week limit on services as inappropriate and short-sighted. A focus on maintenance and preventative services through adequate funding is more likely to avert acute episodes. Moreover, clients with an acute occurrence of mental illness usually have an underlying chronic condition that still requires care once the incident has been resolved. Removal of services either at the end of two weeks or when the condition is stabilized may result in a relapse, triggering another acute episode. While we recognize the issues of sustainability and available funding, the decision to provide only two weeks of services does not address the downloading of hospital costs to the community and the entitlement to care equivalent to that provided in hospitals.

Unlike patients with physical needs, persons living with a mental illness require a much broader range of community supports and services both inside and outside the health sector to prevent relapse. In considering the provision of services, at a minimum, case management, professional services, and medications and medications management should be fully publicly funded. Support services need to be available in the same way and on the same terms as they are for physical/functional conditions whether through home care programs or through community mental health. Because of the special challenges of treatment compliance with this population, consideration needs to be given to the inclusion of services such as transportation that are not traditionally publicly funded by home care programs. Many acute mental health services are delivered in the community (e.g., agency offices) and clients who may be resistant to treatment must travel to these sites. Furthermore, because of the high rate of mental illness among the homeless population, housing requires some attention. This is not to say that the health care system need provide these services, but rather that coordination with other ministries is required.

First-dollar coverage does not preclude the imposition of user charges, as stated above. Charges or co-payments may be unsuitable for this population since stabilization depends on patient compliance with treatment. Because of the nature of mental illness and the side effects of drugs, some clients are resistant to taking their medication. In addition, more so than in other sectors of health care, a higher proportion of people living with a mental illness are on social assistance or are homeless without disposable financial resources. Accordingly, user charges or co-payments may impede the delivery of services or treatment.

Existing acute community mental health services are currently provided through mental health programs and not through home care programs. The First Ministers' agreements are silent on whether these services should be transferred to home care programs. Most key informants concur with the provinces that these services should remain within the mental health sector, where the expertise lies, with a transfer of the appropriate resources targeted for home care to ensure a national standard in acute community mental health.



Although the mental health sector has made strides in improving integration with the primary and acute care sectors, much more needs to be done. Because clients with mental illness also have physical or functional needs, better coordination and integration must exist between the mental health and home care sectors. Traditional home care services should be made available to this population based on need. Innovations and reform should continue to explore better ways of integrating the care of persons living with a mental illness and/or addictions, and these reforms should encompass the spectrum of health care: primary care, home and community care, and acute care.

### **End-Of-Life Care – Promises, Status and Gaps**

More than 220,000 Canadians die each year, 75 per cent of them in hospitals and long-term care facilities. It has been estimated that 160,000 need palliative/ end-of-life care services. Only five to 15 per cent receive integrated and interdisciplinary palliative care. Recent polls suggest that while 90 per cent of Canadians wish to remain in their own homes during the final stages of life, only six per cent of informal caregivers feel they can adequately care for a family member without palliative care support.

While most provinces and territories indicate that they provide some measure of palliative care, the type, volume and regional availability of services provided vary considerably. Who pays for palliative care largely depends on whether the client is in hospital or at home. Palliative care provided in hospital is usually paid by provincial health plans where the costs of care, drugs, supplies and equipment are covered. Residents in long-term care facilities often have to pay part of the costs of palliative care, with costs varying among facilities. Eligibility of home palliative/end-of-life care often requires a physician referral and a prognosis of death within a set time frame, usually six months. In some jurisdictions, clients must declare that they are no longer seeking curative treatment. Provinces with formal home care programs pay for nursing, physician services, rehabilitation therapies, personal support, some requiring co-payments. Provincial home palliative care programs may place limits on the amount of professional and personal support services paid for publicly. Coverage of drugs and equipment used at home varies from fully publicly funded, partially publicly funded, funded by government as the payer of last resort, or not funded.

The requirement by some jurisdictions to predict the likely time of death creates practical and emotional difficulties for physicians, patients, and their caregivers. Given that the First Ministers' 2004 plan places no limit on the amount of service, it may be more suitable that eligibility criteria not include a likely period to death. In addition to case management, nursing, palliative-specific drugs and personal care, entitlements should also include the cost of equipment and supplies, on the premise that these costs would be covered if the patient was hospitalized for end-of-life care.

On January 4, 2004, Canadians became eligible for the new federal compassionate care benefits under the *Employment Insurance Act*. On the basis of a physician referral, the benefit will provide a maximum of six weeks of employment insurance for employees

who need to be absent from work to provide care or support for a family member who is gravely ill with a significant risk of death (within 26 weeks). Most provincial/territorial jurisdictions have amended their labour legislation, increasing job protection to ensure that their populations can take advantage of the federal benefit without risking their employment status. The *Canada Labour Code* was amended to provide federal employees with job protection.

### **Home Care Reporting**

Because home care programs have developed in response to local needs, available resources, and in the absence of national standards, they vary considerably across federal, provincial and territorial jurisdictions. National monitoring and reporting on home care have been confounded by a number of factors, which include:

- lack of a common definition for home care and common services in each province;
- lack of comparable assessment and measurement tools;
- a mix of paper and electronic records;
- different financial capabilities to invest in information infrastructure;
- inability to exchange information across different systems; and
- lack of a common protocol for reporting home care information.

Over the last few years, under the leadership of the Canadian Institute for Health Information (CIHI), considerable progress has been made in developing and piloting national performance indicators for home care. A number of jurisdictions have adopted common or comparable assessment tools. CIHI is currently developing a reporting system for home care to assist all provinces and territories to participate in national reporting.

### **Conclusions And Recommendations**

The Working Group on Home Care has the following recommendation for First Ministers as they proceed to implement the 2004 plan and consider future improvements to home care and health care for Canadians:

- Greater clarity of definitions, eligibility criteria, and functions of short-term acute home care, acute community mental health, and end-of-life care is needed.
  - “Short-term acute home care” should include not only post-hospital care but also care for acute episodes to prevent hospitalization or placement in a residential facility.
  - “Acute community mental health home care” should be defined broadly enough to include clients with substance abuse problems and concurrent disorders.

- There needs to be clarity around the terms “end-of-life” and “palliative” care. Physicians may be reluctant to predict death with the required precision of six months and caregivers are faced with the uncertainty of when to apply for compassionate care benefits. The requirement for a diagnosis of death within six months should be reviewed to determine if it creates a significant barrier to uptake of compassionate care benefits; flexibility should be considered.
- First Ministers need to ensure that the basket of services for each home care target program is considered to be a minimum standard. Jurisdictions should be encouraged to include those services that would not only be a substitute for comprehensive, universal, and accessible institutional care, but are also tailored for each targeted population. For example:
  - The basket of services for short-term acute home care should be reviewed consistently across jurisdictions to consider the inclusion of treatments and services, such as rehabilitation therapies, which can provide substantive, long-term benefit.
  - The basket of services for acute community mental health should take into account the unique nature of mental illness and addictions, and include such services as the cost of medications, and transportation, and a focus on maintenance and prevention functions which are more likely to avert acute episodes of chronic conditions; and
  - Supplies and equipment are often a costly component of end-of-life care and the cost of including them in the basket of services, along with the implications of not including them, should be thoroughly examined.
- Setting service limits for the core basket of services not be cost-efficient for the health care system. Rather, services should continue for as long as they are needed to prevent a relapse. Clients who are stabilized but still require some care and support should be linked and transitioned into other programs.
- Governments should be encouraged to provide full-dollar coverage to ensure universality across Canada; clients should be certain that they will receive comparable services whether they are at home or in hospital. Full-dollar coverage most closely compares to the coverage currently provided for hospital care. User fees and co-payments are a possibility with first-dollar coverage.
- Acute community mental health services should be delivered through the mental health sector, where the expertise lies, with better integration and coordination with the home care sector. Imbalances in the way funds are allocated between these sectors should be addressed.
- Compassionate care benefits are provided through the Employment Insurance program. This mechanism leaves a gap for those not eligible for EI. The federal government should explore ways to also provide compassionate care benefits to those Canadians not working within the coverage of the Employment Insurance program.

- CIHI is encouraged to continue its work with all jurisdictions with respect to the development of data standards, performance indicators and the adoption of common or comparable clinical assessment tools and to implement nationwide data collection.
- The federal government supports the development of electronic client record systems in the provinces and territories through such publicly funded bodies such as Canada Health Infoway. Consideration must be given to providing similar support for the collection and reporting of home care information.
- All jurisdictions should build upon current best practices and technology in expanding services to rural and remote areas.
- All jurisdictions should explore new training models and a human resource strategy to ensure the mix of appropriate personnel required to provide quality care.
- All jurisdictions should recognize through funding the importance and effectiveness of the preventive and maintenance functions of home care in promoting health, maintaining independence, and preventing deterioration of health status, as well as advancing the sustainability of the health care system.
- The First Ministers should expand and enhance the range of accountability mechanisms and where possible, encourage increased citizen engagement with respect to home health care.
- Jurisdictions must explore and develop new models of care that focus on the needs of the patients rather than the organization of providers and the administrative needs of government, and take into account community and social health issues.
- All jurisdictions should explore the role of and the need to support informal caregivers in the home care context.
- All jurisdictions should consider integrating community and social services within the sphere of home care.
- All jurisdictions should consider how chronic disease management fits within home care.
- The Ministers of Health and Federal/Provincial/Territorial advisory committees are encouraged to explore greater integration of the various elements of the 2003 and 2004 agreements on health care renewal. Examples could include, but are not limited to, the integration of primary health care reforms with home care reforms, or the integration of action on health human resources (such as inter-professional education, workplace health, and health human resources planning) with other elements of accords.
- Funding agencies should be encouraged to promote and support research into home health services, including cost effectiveness.

## 1.0 Introduction

### 1.1 What have governments promised?

The home health care sector is a growth sector. However, these vital programs have not, until recently, received the attention and funds they need to fulfill their mandates and potential. Though home care programs exist in all Canadian provinces and territories, some are more established than others. The 1990s saw considerable growth in this sector, stimulated by a number of demographic factors and policy reform initiatives, including an aging population, hospital downsizing along with shorter lengths of stay, as well as technological and medical advancements that allowed for more care to be provided safely in the home. However, hospital downsizing and shortened lengths of stay have outpaced the development and expansion of home care programs. As a result, family and volunteer caregivers have been shouldering an increasing amount of the need for care.

Through the 2003 First Ministers' Accord on Health Care Renewal Accord, the 2004 10-Year Plan, and in keeping with the recommendations of the Romanow Commission<sup>1</sup> and the Kirby Committee<sup>2</sup>, the First Ministers targeted home care for an infusion of funds and made it a priority area for reform.<sup>3</sup>

The 2003 Accord stated:

Improving access to **a basket of services** in the home and community will improve the quality of life of many Canadians by allowing them to stay in their home or recover at home. **First Ministers direct Health Ministers to determine by September 30, 2003, the minimum services to be provided.** Such services provided in the home can be more appropriate and less expensive than acute hospital care. To this end, First Ministers agree to provide first-dollar coverage for **this basket of services** for short-term acute **home care**, including acute community mental health, and end-of-life care. First Ministers agree that access to these services will be based on assessed need and that, by 2006, available services **could** include nursing/professional services, pharmaceuticals and medical equipment/supplies, support for essential personal care needs, and assessment of client needs and case management. The Government of Canada will complement these efforts with a compassionate care benefit through the Employment Insurance Program and job protection through the Canada Labour Code, for those who need to temporarily leave their job to care for a gravely ill or dying child, parent or spouse. [Emphases in the original.]<sup>4</sup>

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<sup>1</sup> Commission on the Future of Health Care in Canada. 2004. *Building on Values: The Future of Health Care in Canada*. [www.hc-sc.gc.ca/english/pdf/care/romanow\\_e.pdf](http://www.hc-sc.gc.ca/english/pdf/care/romanow_e.pdf).

<sup>2</sup> Standing Senate Committee on Social Affairs, Science and Technology. 2002. *The Health of Canadians-The Federal Role: Final Report on the State of the Health Care System in Canada*.

<sup>3</sup> Federal/Provincial/Territorial First Ministers. 2003. *2003 First Ministers Accord on Health Care Renewal*. [www.hc-sc.gc.ca/english/hca2003/accord.html](http://www.hc-sc.gc.ca/english/hca2003/accord.html).

<sup>4</sup> Federal/Provincial/Territorial First Ministers. 2003. *2003 First Ministers Accord on Health Care Renewal*. *ibid*.

In addition, First Ministers agreed to report to Canadians:

First Ministers agree to prepare an annual public report to their citizens on each of the above three areas commencing in 2004. They further agree to use comparable indicators and to develop the necessary data infrastructure for these reports. This reporting will inform Canadians on progress achieved and key outcomes. It will also inform Canadians on current programs and expenditures, providing a baseline against which new investments can be tracked, as well as on service levels and outcomes.

Although they did not meet the September 30, 2003, date for defining a minimum basket of services for the three home care program areas, the First Ministers did reach consensus in September 2004. The 2004 10-year plan states:

All governments have recognized the value of home care as a cost-effective means of delivering services and are developing home care services to prevent or follow hospitalization.

First Ministers agree to provide first-dollar coverage by 2006 for certain home care services, based on assessed need, specifically to include:

- Short-term acute home care for two-week provision of case management, intravenous medications related to the discharge diagnosis, nursing and personal care;
- Short-term acute community mental health home care for two-week provision of case management and crisis response services; and
- End-of-life care for case management, nursing, palliative-specific pharmaceuticals and personal care at the end-of-life.

Each jurisdiction will develop a plan for the staged implementation of these services and report annually to its citizens on progress in implementing home care services. First Ministers task their Health Ministers to explore next steps to fulfill the home care commitment and report to First Ministers by December 31, 2006.<sup>5</sup>

## *1.2 What do we mean by home care?*

Home care has been defined by the Federal/Provincial/Territorial Working Group on Home Care “as an array of services which enables clients incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives.”<sup>6</sup> As a recent pilot study showed, services may not necessarily be received at home but rather, the receipt of services, whether in the

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<sup>5</sup> Canadian Intergovernmental Conference Secretariat. A 10-year plan to strengthen health care. First Ministers’ Meeting, September 13-15. September 16, 2004. [www.scics.gc.ca/cinfo04/800042005\\_e.pdf](http://www.scics.gc.ca/cinfo04/800042005_e.pdf).

<sup>6</sup> Federal/Provincial/Territorial Working Group on Home Care, Health Services and Promotion Branch, Health Canada. 1990. *Report on Home Care*.

home or in the community, enables clients to remain at home.<sup>7</sup> Furthermore, the federal/provincial/territorial report states that home care is a health program, with health broadly defined; as such, its effectiveness also relies on what might otherwise be considered social and educational services such as home maintenance and volunteer visits. The report's definition recognizes three distinct functions of home care – prevention, maintenance and substitution. While these functions are widely accepted, their definitions may differ, for example:

- *prevention* - preventing decline in health and functional status;
- *maintenance* – maintaining for as long as possible the independence of clients in their home through health and social support services; and
- *substitution* – providing a substitute for institutional settings in the delivery of acute care.<sup>8</sup>

Or

- a *preventative* function, which invests in client service and monitoring at additional short-run but lower long-run costs;
- a *maintenance* function that allows clients to remain independent from a new and more costly venue;
- a *substitution* function for services provided by hospitals and long-term care facilities.<sup>9</sup>

Clients of home care services are as varied as the population. They span all ages, have diverse needs, receive different services and supports for differing lengths of time, and have different expected outcomes. How jurisdictions meet the needs of their populations varies considerably in terms of eligibility criteria and types of services provided; in terms of who delivers the services (for-profit, not-for-profit or government agencies); and in terms of what and how much of the service is publicly funded. Services may be received in the home, in the community, over the telephone, or in some cases, through the Internet.

A comprehensive summary of provincial/territorial programs can be found elsewhere.<sup>10 11</sup> In general, all home care programs use a single point of entry to access home care services, and provide assessment and case management services. In addition, all programs provide a core set of services which include nursing care and home support (personal support and some measure of homemaking). However, the nature of available nursing services varies from complex clinical care to monitoring support. The provision of physiotherapy, occupational therapy, speech therapy, nutrition, social work, medical supplies and equipment varies considerably across provinces/territories and sometimes

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<sup>7</sup> Canadian Institute for Health Information (CIHI). 2004. *Development of National Indicators and Reports for Home Care – Phase 2: Project Report*.

<sup>8</sup> Ballinger, G, J Zhang, V Hicks (updated by C Gyorfi-Dyke). 2003. *Monitoring the Feasibility of Reporting Home Care Estimates in National Health Expenditures*. Canadian Institute for Health Information.

<sup>9</sup> Canadian Home Care Association. 1998. *Portrait of Canada: An Overview of Home Care Programs*.

<sup>10</sup> Canadian Home Care Association. 2003. *Portraits of Home Care: A Picture of Progress and Innovation*.

<sup>11</sup> Ballinger G et al. 2003. *ibid*.

within those jurisdictions. Drugs, psychiatric/mental health services, and palliative care, when available, are often accessed through other programs. The social support services (e.g., meals on wheels, security checks, friendly visiting) can usually be accessed directly by clients or through home care programs. The core home care services of assessment, case management and nursing care are publicly funded, usually with a limit on total hours of service. Co-payments and income testing usually apply to personal support services, health care providers other than nurses, medical supplies/equipment, and social support services.

Some emerging concerns about home care include:

- increasing demand and financial sustainability of public funding;
- a decrease in focus on the maintenance and preventive functions of home care due to an increasing focus on acute care substitution;
- barriers to accessibility of home care services by certain population groups (e.g., First Nations, Inuit, ethnic minorities);
- reduction in home support services despite demand and evidence of their effectiveness;
- an associated shift of responsibilities to family caregivers;
- an increase in privately funded home care;
- shortages of services and providers in rural and remote areas; and
- increasing use of technology.<sup>12</sup>

Although health care, including home care, is commonly seen as the responsibility of provincial/ territorial governments, the federal government also provides home and continuing care services for Canadians not covered by provincial health programs. These include members of the Canadian Forces, veterans, members of the RCMP who are appointed to a rank, individuals serving a term of imprisonment in a penitentiary, and First Nations and Inuit living on a First Nations reserve or Inuit settlement. Ten federal departments provide health care to one million federal clients at an annual cost of \$2.6 billion. To reduce costs and improve services to clients, these 10 federal departments formed the Federal Healthcare Partnership (FHP) in 1994. Health Canada represents these departments in the federal/provincial/territorial meetings and on the Deputy Ministers Advisory Committees. The FHP meets regularly to set policy and inform Health Canada of circumstances in their respective programs.

### *1.3 What is covered in this report?*

This background paper highlights the progress the federal, provincial, and territorial governments have made in implementing the home care reforms from the time of the 2003 First Ministers' meeting:

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<sup>12</sup> Canadian Home Care Human Resources Study. 2003. *Synthesis Report*. Government of Canada.



- the determination of a minimum basket of services;
- the provision of first-dollar coverage for this basket of services for short-term acute home care, acute community mental health, end-of-life care by 2006;
- the development of a federal compassionate care benefit through the Employment Insurance Program and job protection through the Canada Labour Code;
- the development of performance indicators for the Accord areas, the necessary data infrastructure to support it, and a report to their publics on progress towards implementing the Accord elements; and
- the challenges and opportunities in improving care for Canadians in this part of the health care continuum.

The 2003 Accord and the 2004 10-year plan do not define their terms with precision, no doubt to allow the provinces and territories some flexibility in interpretation and development of programs. Accordingly, a portion of this paper will outline the possible interpretations of key terms and the likely effects of each interpretation.

## 2.0 Methods

The data and information for this report were collected from a number of different sources:

- review of the academic and grey literature;
- responses to questionnaires sent to all federal, provincial, and territorial jurisdictions requesting information on home care and in particular, the three home care elements outlined in the 2003 Accord and the 2004 10-year plan;<sup>13</sup> (Appendix 1).
- responses to interviews with key informants in areas of short-term acute home care, acute community mental health, end-of-life care, assessment tools, data measurement, and development of performance indicators (Appendix 2); and
- search of relevant government and organizational websites.

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<sup>13</sup> By the deadline for the provincial survey, not all provinces had responded. The jurisdictions who responded to the survey are: Yukon, Northwest Territories, Saskatchewan, Manitoba, Nova Scotia, Prince Edward Island, Newfoundland/Labrador, and the federal government programs (Veterans Affairs Canada, Indian and Northern Affairs, RCMP, and Health Canada). Ontario provided background documents. New Brunswick partially completed the survey. Other jurisdictions referred the author to their websites. Unfortunately, the information being sought was not always found on the websites.

### 3.0 A Minimum Basket Of Services

The First Ministers agreed to determine a minimum basket of services for home care programs by September 2003, such that Canadians, regardless of where they live, can expect to have available the same set of home care services. In 2004 they outlined the basket of services and time limits for the three program areas. The Accord and the 10-year plan do not say that all these services need be fully publicly funded for all home care clients. Rather, they state that there should be first-dollar coverage for short-term acute home care, acute community mental health, and end-of-life care. In the insurance literature, “first-dollar coverage” means there is no deductible that the individual must pay either through private insurance or out of pocket. As a result, first-dollar coverage can mean full public funding with no deductibles, or it can mean public funding with no deductibles but with user charges or co-payments.<sup>14</sup> Succinctly put, first-dollar coverage does not necessarily mean full-dollar coverage. Provincial/territorial programs could charge or continue to charge user fees for home care services in the basket.

The 2003 Accord further suggests that, by 2006, the minimum basket of services could include nursing/ professional services, pharmaceuticals and medical equipment/supplies, support for essential personal care needs, and assessment of client needs and case management. In 2004 the First Ministers agreed on the services to be included in each program area, although this fell somewhat short of the services that were proposed in 2003. For short-term acute home care and acute community mental health they placed a two-week maximum limit on services. Regardless of the interpretation of first-dollar coverage, the time limit on services is likely an attempt to limit financial exposure and is perhaps based on the belief that most patients of acute episodes of either a physical or mental nature are cured or stabilized within that time period. The impact on clients of these services is discussed below.

### 4.0 Short-Term Acute Home Care

#### 4.1 What have governments promised?

While instructing Health Ministers to provide first-dollar coverage for a minimum basket of services for short-term acute home care, the 2003 Accord and the 2004 plan are both silent on the definition of short-term acute care. It was agreed in the 2004 plan that first-dollar coverage will be provided for a two-week provision of care no later than 2006.

Services should include:

- case management;
- intravenous medications related to the discharge diagnosis;
- nursing; and
- personal care.

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<sup>14</sup> Morgan S, Wilson D. 2004. Post-Romanow Pharmacare: Last-Dollar First ... First-Dollar Lost? *Healthcare Papers* 4 (2).

Clarity on the definition of short-term acute home care (STAHC) is essential to understand the breadth and scope of the program. Without guidance from the language of the First Ministers' agreements, we consulted other reports and government responses to our survey for definitions.

#### 4.2 What do we mean by short-term acute home care?

All of the sources reviewed clearly intend short-term acute home care to be a substitute for hospital care. However, where sources differ is on whether STAHC should be reserved for post-hospital care or whether it should be provided to clients experiencing an acute physical/functional episode to prevent hospitalization.

The Romanow Commission recommended that post-discharge (hospital discharge) acute home care be publicly funded as it represents a substitute for services that previously would have been covered in hospital. "Providing coverage under the *Canada Health Act* would support the current trend to increasing care at home and ensure that post-acute home care is available on the same terms and conditions across the country."<sup>15</sup> The Commission indicated that case management, health professional services and medication management be included in the basket of services and that care should be provided for a maximum of two weeks following discharge from acute care or a maximum of four weeks if rehabilitation is required.

The Kirby Committee also highlighted post-discharge acute home care as opposed to short-term acute care. It defined post-hospital care as "the provision of home care services to patients who have experienced an episode of hospital care. ... Post-acute home care recipients should be defined as individuals who received their first home care visit within 30 days of their in-patient or same-day hospital discharge date."<sup>16</sup>

The Federal/Provincial/Territorial Home Care Basket of Services Working Group defined short-term acute home care as the provision of a basket of health and support services to individuals experiencing an acute episode of illness or injury. The goal is to avoid admission to or reduce the length of stay in an acute care facility/hospital.

In a fact sheet on the 2003 Accord, Health Canada has defined short-term acute home care as including "post-surgical care, rehabilitation, or health instructions on care or the use of medical equipment for chemotherapy, oxygen therapy, diabetes, IV therapy, or medication administration; and care to clients with acute serious mental illness."<sup>17</sup>

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<sup>15</sup> Commission on the Future of Health Care in Canada, 2002 *Building on Values: The Future of Health Care in Canada. Final Report*. p.181.

<sup>16</sup> Standing Senate Committee on Social Affairs, Science and Technology, 2002. *The Health of Canadians – The Federal Role*. Volume 6: Recommendations for Reform. p17-18.  
[www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repoct02vol6-e.htm](http://www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repoct02vol6-e.htm).

<sup>17</sup> Health Canada. Home Care for Canadians. [www.hc-sc.gc.ca/english/hca2003/home\\_care.html](http://www.hc-sc.gc.ca/english/hca2003/home_care.html).

The 2004 10-year plan states that governments “are developing home care services to prevent or follow hospitalization.”<sup>18</sup> This statement comes in the preamble on service provision for the three home care areas; however, the plan does not specifically task governments on this point.

CIHI defines an acute home care client as a “client with acute health or post surgical condition(s) with clearly identified and predictable outcomes or expected recovery.” It goes on to define acute care substitution as “specialized health and support services provided to individuals that are intended to promote recovery from an acute episode of illness or surgery and/or for individuals recently discharged from hospital. Services are time-limited and may vary from low to high intensity. The goals of these services are to prevent an acute care facility admission or re-admission and/or to reduce the length of stay in an acute care facility.”<sup>19</sup>

The working definitions of short-term acute home care in the federal, provincial, and territorial jurisdictions are provided in Appendix 3.

#### *4.2.1 What challenges arise from variations in definition?*

Short-term acute home care is clearly intended as a substitute for hospital care. What is less clear from the 2003 Accord and the 2004 plan is whether or not it refers only to care following hospital discharge or if it also includes an acute episode that requires home care to prevent hospitalization. The Senate Committee and the Romanow Commission both intended STAHC for post hospital care. While the Accord does not shed light on this question, Health Canada on its Renewal Accord 2003 website states that the benefits of home care for Canadians include prevention of hospitalization and reduced lengths of stay in the hospital.<sup>20</sup> CIHI and the FPT Working Group appear to include both forms of substitution for hospital care. The federal departments, provinces and territories in their current policies either:

- do not address the issue (Veterans Affairs Canada, INAC Assisted Living Program, Newfoundland, Manitoba),
- do not address the issue but accept CIHI’s definition of an acute home care client<sup>21</sup> (Yukon, Northwest Territories)
- reserve it for post hospital discharge (First Nations and Inuit Home and Community Care),
- rule out post hospital discharge home care (Nova Scotia),
- accept both the preventive and post hospital discharge substitute function (Health Canada, RCMP, Saskatchewan);

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<sup>18</sup> Canadian Intergovernmental Conference Secretariat. 2004. *ibid.*

<sup>19</sup> Canadian Institute for Health Information. 2004. *Development of National Indicators and Reports for Home Care – Phase 2: Project Report. Draft.*

<sup>20</sup> Health Canada. Home Care for Canadians. *ibid.*

<sup>21</sup> “Client with acute health or post surgical conditions with clearly identified and predictable outcomes or expected recovery.”

- do not provide clarity (It is unclear whether PEI's definition only applies to patients who have been previously hospitalized for the condition to be cared for at home.).

Much discussion has revolved around hospital substitution as a cost-effective function for home care, but what about substitution for residential care? While evidence suggests that elderly clients who experience an acute need are often prematurely admitted into residential care, it is not clear if the prevention of inappropriate admission to nursing homes is or should also be one of the functions of STAHC.

There is considerable divergence between the various recommendations on time of service provision and the actual length of short-term acute home care service provided in Canada's jurisdictions. Times vary from two weeks (Romanow for acute care discharge, 2004 plan, Newfoundland, Nova Scotia [15 days with exceptions]) to 60 days (Manitoba) to three months (NWT). Others refer to time-limited services but do not further specify (CIHI, Yukon, PEI) or are silent on the subject (Saskatchewan). Finally, the Standing Senate Committee in defining STAHC refers to home care services that begin within 30 days from hospital discharge. Mr. Romanow also makes the distinction between post acute and post rehabilitation home care, recognizing that the latter usually requires a longer period of service (four weeks).

In its fact sheet on the 2003 Accord, Health Canada indicates that one of the potentials of home care is to "reduce the pressure on the health care system by ensuring that patients receive medically necessary services at home, instead of the hospital. Many such services provided in the home are more appropriate and less expensive than hospital care."<sup>22</sup> If one of the intents of the 2003 Accord is to reserve hospital services for those situations where the home is neither suitable nor safe, then the definition should include both forms of substitutive acute home care.

If another intent of STAHC is to ensure that services fully funded in hospital continue to be funded in the home, it is not clear why the 10-year plan imposes a time limit on services or why the term first-dollar coverage is not clearly defined. The *Canada Health Act* mandates public funding for all medically necessary services, does not impose time limits, and discourages user fees.

It is understandable that provinces are concerned about the sustainability of funding. For this reason, some have argued that hospital savings from home care substitution should be re-allocated to short-term acute home care. Others have argued that post acute home care should become the responsibility of hospitals, to discourage cost-shifting and downloading from one sector to the other.<sup>23</sup>

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<sup>22</sup> Health Canada. Home Care for Canadians. *ibid.*

<sup>23</sup> Coyte P. 2002. Expanding the Principle of Comprehensiveness from Hospital to Home. Submission to the Standing Committee on Social Affairs, Science and Technology. July 17, 2002. [www.hcerc.utoronto.ca/PDF/Report1.PDF](http://www.hcerc.utoronto.ca/PDF/Report1.PDF).

#### 4.3 What do we know about the need for short-term acute home care in Canada?

Technological and medical advancements as well as hospital restructuring have led to more patients being cared for in the home, thereby avoiding hospitalization completely or shortening the length of the hospital stay. However, as in de-institutionalization of psychiatric patients, the necessary community programs have not been in place across and within all jurisdictions. The literature suggests that home care may be a cost-effective alternative to hospital care but recent evaluations have been mixed.<sup>24 25</sup>

The Standing Senate Committee estimated that in 1996-97 acute home care clients comprise anywhere from 17 per cent (Yukon) to 56 per cent (British Columbia) of the home care population, with a Canadian average of 33 per cent. The nature of care provided varies by the type of client. Care provided to short-term clients consists of nursing services (63 per cent), personal support (21 per cent) and other therapies (16 per cent). In contrast, care to continuing care clients is largely made up of personal support (59 per cent), followed by nursing care (36 per cent).<sup>26</sup>

Poor discharge planning and a shortage of home and community support services have led to emergency room congestion and to patients being cared for in hospital longer than necessary, as well as an increase in the use of Alternate Level Care beds.

#### 4.4 What services do the jurisdictions currently provide?

Short-term acute home care is provided through home care programs. The provision and public funding of STAHC services to a large extent mirrors general home care services. As described earlier, some jurisdictions have limits on how long a client can be provided short-term acute home care services or a dollar limit usually equivalent to the cost of institutional care.

Most jurisdictions provide:

- assessment and case management (fully funded by all jurisdictions);
- nursing (fully funded by all jurisdictions, although some put a time or visit limit on the service);
- physiotherapy, occupational therapy, and speech language therapy (less frequently offered) – the availability of rehabilitation services may vary within jurisdictions;
- essential personal care (some jurisdictions fully fund it while others charge a co-payment; in one jurisdiction it is provided by another ministry)

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<sup>24</sup> Hollander M. 1996. *The Cost-Effectiveness Of Continuing Care Services: A Critical Literature Review*. Victoria: Health Network, Canadian Policy Research Networks.

<sup>25</sup> Hollander M & Chappell N. 2002. *Synthesis Report: Final Report of the National Evaluation of the Cost-Effectiveness of Home Care*. A report prepared for the Health Transition Fund, Health Canada.

<sup>26</sup> Standing Senate Committee on Social Affairs, Science and Technology, 2002. *The Health of Canadians – The Federal Role*. Volume 6: Recommendations for Reform.

- nutrition (provided free by some jurisdictions);
- medical equipment (provided by only a few jurisdictions; restricted by age of client; dependent on availability);
- medical supplies (provided by some jurisdictions); and
- drugs (if provided, often provided through a separate program; may be restricted to seniors, people on social assistance, or those with chronic diseases).

Appendix 4 describes current services or programs for short-term acute home care in each of the federal, provincial and territorial jurisdictions that responded to the survey questionnaire.

#### 4.5 What do Canadian jurisdictions currently do well?

Many jurisdictions have been developing, piloting and implementing innovative programs to deliver short-term acute home care. These programs address a number of different issues – for example, the interface between home care and primary care, special types of care, or special populations.

Elements of best practice in these programs include:

- quick response;
- multidisciplinary teams;
- coordination, integration and communication across the *continuum* of care from prevention, primary care to acute care;
- availability of 24/7 coverage; and
- a basket of services that includes professional services (nursing, rehabilitation therapies, social work, nutrition, pharmacy) medical equipment/supplies, drugs, essential personal support, and homemaking and community supports services when needed.

The following programs highlight some examples of innovation in Canada.

- Quick Response Program in Saskatoon;
- Comprehensive Home Option of Integrated Care for the Elderly (CHOICE) in Edmonton;
- Integrating Physician Services in the Home in London, Ontario;
- The Toronto Community Care Access Centres Wound Care Framework;
- The East York (Ontario) Telehomecare Project; and
- Extra-Mural Program in New Brunswick.

Appendix 5 contains a description of these programs.

#### *4.6 What are the gaps in services and funding? What strategic improvements are suggested?*

There is growing consensus within Canada that short-term acute home care should be considered akin to medically necessary services as defined under the *Canada Health Act*. Although short-term acute home care programs are largely in place in all jurisdictions, there is considerable variation in funding and availability of these services across Canada. As a result, these services are neither universally available to Canadians nor uniformly accessible. Values of fairness and equity require a national standard of program elements.

Although a full year transpired without consensus, the First Ministers did reach an agreement on a basket of services in September 2004. Although the two-week limit on services and first-dollar coverage recommended are probably reasonable given the progress of most acute episodes and the desire of jurisdictions to limit their liability, the basket should focus instead on providing full-dollar coverage for care in the home that would otherwise be provided in hospital. For those clients requiring more than two weeks of service, the STAHC program may represent not just a substitute for hospital care but a *de facto* reduction in benefits under the *Canada Health Act*. The agreed upon basket specifies assessment, case management, nursing and personal care. Intravenous medication is to be provided only if it relates to the discharge diagnosis, which implies that it will be available only following hospital discharge. Notably absent are rehabilitation therapies, which are crucial for certain conditions and procedures such as stroke and hip/knee replacement. Key informants strongly recommend that the basket of services specifically include rehabilitation therapies and any other services that would have been fully funded if provided in an acute care facility. Moreover, STAHC should be viewed not only as a cost-effective alternative to hospital care that can be safely provided in the home, but also as an option for care that may be therapeutically best for the patient.

## **5.0 Acute Community Mental Health**

### *5.1 What have governments promised?*

The 2003 Accord, and the 2004 plan, while instructing Health Ministers to determine a minimum basket of services for acute community mental health, were silent on the definition of acute community mental health. It was agreed in the 2004 plan that first-dollar coverage will be provided for a two-week provision of care no later than 2006. Services should include:

- case management and
- crisis response services.

### *5.2 What do we mean by acute community mental health care?*



The preamble to the First Ministers' 2004 plan states that home care service "can be an effective option for some patients with chronic mental health concerns." The Ministers follow the statement with an agreement to provide a basket of services for short-term acute community mental health home care without defining the terms. A review of reports and jurisdiction responses to our survey shed some light on the meaning of acute community mental health.

The Romanow Commission recommended that new federal funding for home care be used to support the expansion of the *Canada Health Act* to include medically necessary services in community-based mental health case management and intervention services.<sup>27</sup> The implication of this recommendation is that community mental health case management and intervention services should be wholly publicly funded entitlements based on medical necessity. Case managers would provide and ensure continuity and coordination of care. Home intervention is intended to assist and support clients who are experiencing "an occasional acute period of disruptive behaviour that poses a threat to themselves or to others and could trigger unnecessary hospitalization."<sup>28</sup> Although the report speaks to acute periods of disruptive behaviour, it also implies that case management support can be helpful for clients with dementia in assessing changing needs, providing necessary care, and planning for a time when they can no longer remain at home.

Sources say that the Federal/Provincial/Territorial Working Group tasked with identifying a basket of services following the 2003 Accord defined acute mental health to include services provided to individuals with an acute mental disorder and/or illness. The goal is to avoid admission and/or reduce the length of stay in an acute care facility/hospital.<sup>29</sup> This definition highlights both substitution functions – prevention of hospitalization and earlier discharge from hospital – that community services can provide.

Appendix 6 provides a summary of jurisdictional definitions of acute community mental health.

### *5.2.1 What challenges arise from variations in definition?*

Some federal, provincial and territorial programs do not have a definition of acute community mental health because these clients are not dealt with through the home care program, while others accept the definition of the FPT Working Group. Alzheimer's disease and dementia are not intended to be included in the eligibility criteria for acute community mental health, no doubt because of the chronic nature of these conditions.

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<sup>27</sup> Commission on the Future of Health Care in Canada. 2002. *Building on Values: The Future of Health Care in Canada*. Final Report.

<sup>28</sup> Commission on the Future of Health Care in Canada. 2002. *ibid.* p. 179.

<sup>29</sup> Government of Newfoundland. 2004. Response to Health Council of Canada Questionnaire to Jurisdictions.

While some sources refer to mental illness as defined by the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM-IV), others intend to include acute disruptive behaviours that pose a threat to self or others. The latter view reflects the fact that clients with acute disruptive behaviours are often inappropriately hospitalized, placed in nursing homes, or become involved with the criminal justice system.

Concurrent disorders – a condition in which a person has both a mental illness and a substance use problem – are identified as a priority issue in the mental health field. However, the First Ministers’ agreements are silent on whether addictions are included in the eligibility for acute community mental health. While it is challenging to determine how many people have a concurrent disorder, it is known that people with mental illness have much higher rates of addiction and those with an addiction problem have much higher rates of mental illness, compared to the general population.<sup>30</sup> People with concurrent disorders are frequently misidentified, because one disorder can mimic another. Relapse rates for substance use or mental illness are higher for people with a concurrent disorder. Depending on the setting, prevalence rates for concurrent disorders have been found to range from 20 to 80 per cent.<sup>31</sup> In an Alberta study, almost one-third of mentally ill individuals also had a substance use problem, almost one-third of those with alcohol dependency also had a psychiatric diagnosis, and among illicit drug users, almost half had a mental illness.<sup>32</sup> High rates of concurrent disorders strain not only the hospital sector but also the criminal justice system.

Best practice guidelines suggest an integrated approach to assessment, treatment and support for concurrent disorders. In some jurisdictions, mental illness and addictions are integrated in the same program area. Knowledge of whether clients with a mental illness have an addiction is important for treatment. Depending on the mental illness, guidelines suggest implementing treatment for the substance use disorder either prior to or concurrent with treating the mental illness. Moreover, the nature of the treatment varies depending on the particular forms of mental illness and substance abuse.<sup>33</sup>

### *5.3 What do we know about the need for acute community mental health care in Canada?*

Governments’ commitment to publicly fund a common basket of acute community mental health services stems from a long history of moving people out of psychiatric institutions without the necessary community services in place to support them.

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<sup>30</sup> Centre for Addiction and Mental Health. Concurrent Disorders. [www.ontario.cmha.ca/content/about\\_mental\\_illness/concurrent\\_disorders.asp?cID=3964](http://www.ontario.cmha.ca/content/about_mental_illness/concurrent_disorders.asp?cID=3964).

<sup>31</sup> Centre for Addiction and Mental Health. “People with Concurrent Disorders” in Virtual Resource for the Addiction Treatment System, Section 3: Special Populations. Available at <http://sano.camh.net/resource/pconc.htm>.

<sup>32</sup> Centre for Addiction and Mental Health. 1998. Answers to Common Questions on Concurrent Disorders. *Journal of Addiction and Mental Health* 16 (September-October).

<sup>33</sup> Health Canada, 2002. Best Practices: Concurrent Mental Health and Substance Use Disorders. [www.hc-sc.gc.ca/hecs-sesc/cds/pdf/concurrentbestpractice.pdf](http://www.hc-sc.gc.ca/hecs-sesc/cds/pdf/concurrentbestpractice.pdf).

Typically, mental health supports and services are not provided through home care programs. Moreover, access to home care services by people with mental illness in some jurisdictions is impeded by a requirement that a concurrent physical or functional problem exist along with the mental illness.

Although a mental health crisis can arise for different reasons, the venue for management has often been a hospital emergency room and the response has too frequently been hospital admission and lack of follow-up upon discharge.<sup>34</sup> In 2001-02, the Canadian Institute for Health Information estimated that the rate of hospitalization for all mental disorders per 100,000 population in Canada was 617.0. This amounted to a total of 8,243,106 inpatient days in hospital, with an average of almost 43 days per patient. No doubt because of the differential availability of community services, hospitalizations for mental disorders vary considerably across the provinces and territories, from a low of 274/100,000 in Nunavut to 1149/100,000 population in Prince Edward Island. The average length of stay in hospitals was considerably higher in Quebec than in other provinces (91 days vs. the Canadian average of 43 days).

#### *5.4 What services do the jurisdictions currently provide?*

The mental health sector, especially its community-based component, has been underfunded compared with other sectors. It includes some of the most vulnerable people in our society, many of whom are homeless.

Most jurisdictions that provide some form of community mental health services deliver them through mental health programs rather than through home care. Nevertheless, there is significant variation in services provided with availability limited by financial and human resources.

Acute community mental health services usually take the form of rapid response and include:

- assessment and intensive case management;
  - crisis services;
  - psycho-social and/or addictions counseling;
  - crisis phone lines;
  - medication management;
  - sometimes rehabilitation services, particularly occupational therapy.
- 
- Medical equipment/supplies, if provided, and personal care often involve a co-payment.
  - Medications, if funded, are usually supported through a separate program.

Jurisdictions with more developed programs provide support 24 hours a day, seven days a week (24/7). Home care programs usually provide services for physical or functional

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<sup>34</sup> Health Canada. 1997. Review of Best Practices in Mental Health Reform. Available at [www.hc-sc.gc.ca/hppb/mentalhealth/pubs/bp\\_review/e\\_sec1rev.html](http://www.hc-sc.gc.ca/hppb/mentalhealth/pubs/bp_review/e_sec1rev.html). Accessed August 16, 2004.

problems, with a few having some mental health support but not for crisis situations. Indeed, some jurisdictions do not provide home care to clients with a mental illness unless they have a physical or functional need.

Appendix 7 provides a summary of current federal, provincial and territorial programs that provide some form of acute community mental health care.

### *5.5 What do Canadian jurisdictions currently do well?*

Case management has increasingly been viewed as a service to help people with mental illness live in the least restrictive environments and as a key strategy to reducing hospital admissions. Case management programs vary in design and have been categorized as:

- Expanded broker model: focuses on coordination and referral to services;
- Rehabilitation model: focuses on improving the client's living skills with managers providing continuous interpersonal support, assistance in dealing with crises, and accessing resources;
- Personal strengths model: focuses on client's strengths and identifies resources and situations to help the client achieve success;
- Full support model: also known as assertive community treatment (ACT), focuses on reducing and managing symptoms. A multidisciplinary team provides case management, 24/7 coverage, and assertive outreach to clients in the community where they live;
- Intensive case management: similar to the full support model but service may also be provided by professionals using the rehabilitation and personal strengths models. Intensive case management is geared to high need individuals and focuses on activities to prevent hospitalization. The team usually includes professionals who can provide intensive levels of support.<sup>35</sup>

Evaluations of the full support model, notably ACT teams, have generally shown reduced hospitalization (admissions, number of inpatient days, length of time to readmission); reduced costs largely due to a decrease in hospital use; cost-effectiveness compared to institutionalization; improved clinical status; high rates of family and client satisfaction; and effectiveness in keeping clients in treatment.<sup>36</sup>

Crisis response systems (CRS) have been proposed as an effective approach for dealing with acute mental health episodes. The usual goals of CRS from the client's perspective are to:

- increase tenure in the community;

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<sup>35</sup> Robinson G & Toff-Bergman G. 1989. *Choices in Case Management: Current Knowledge and Practice for Mental Health*. Washington, DC: Mental Health Policy Resource Center. As cited in Health Canada. 1997. Review of Best Practices in Mental Health Reform. *ibid*.

<sup>36</sup> Health Canada. 1997. Review of Best Practices in Mental Health Reform *ibid*.

- maximize the person's ability to recognize and deal with situations which might result in crises; and
- to increase the person's network of community supports and use of that network.

From a system perspective, the goals include:

- timely and accessible care from a range of options; and
- stabilization as quickly as possible for the client.

CRS encompasses an integrated range of services and offers back-up to community mental health providers, family practitioners and the police. The functions of CRS have been broken down into crisis specific functions and pre-crisis and ongoing support functions.

Crisis specific functions include:

- telephone crisis services;
- walk-in crisis intervention services;
- mobile crisis outreach;
- short-term residential placements for crisis stabilization in protective and supportive settings; and
- medical services including inpatient services when other options have been exhausted.

Pre-crisis and ongoing support functions include:

- crisis prevention services such as
  - peer support networks;
  - family support;
  - intensive case management;
  - in-home support programs; and
- ongoing supportive services such as
  - case management;
  - natural supports;
  - drop-in centres;
  - housing support; and
  - financial support.<sup>37</sup>

Mobile Crisis Outreach teams are intended to link users to community support services. This process is facilitated if the team is part of a community mental health program such as an assertive case management program or if there are established access channels with community programs. Teams either operate on a 24-hour basis or only during hours when other community programs are closed. Although there have been few evaluations of crisis response systems, the literature reports reduced hospitalization, costs, and better patient outcomes when a psychiatrist is attached to the team; the psychiatrist is able to make

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<sup>37</sup> Health Canada. 1997. Review of Best Practices in Mental Health Reform. *ibid.*

timely decisions regarding medication and provides support to family and other informal caregivers.<sup>38</sup>

Early Intervention Programs for first time psychoses have been recognized as a best practice. First episodes or psychoses often emerge during adolescence and early adulthood. Delays in the treatment of psychosis have been associated with substantially higher health care costs for at least three years after first treatment. In addition, long-term “treatment resistant” symptoms and the “revolving door of admissions” have their origins in the critical early period.<sup>39</sup> Studies show that with prolonged delay between the onset of psychosis and treatment, patients become less responsive to treatment and require a longer recovery period.

A number of innovative practices in the area of acute community mental health have been developed across Canada since the early 1990s. Elements of best practices include quick and early response; comprehensive assessment; multidisciplinary teams that include psychiatric back-up; coordination/ integration/ communication across the continuum of care; intensive case management and 24/7 support; medication management and compliance; family engagement; peer support; and support for the reintegration into school and work activities.

Some innovative programs include:

- Fraser Health Region, BC Early Psychosis Intervention Program;
- Taber (Alberta) Mental Health Community Care Pilot Project;
- Manitoba’s Program for Assertive Community Treatment;
- Ontario’s First Episode Psychosis Program;
- Hamilton COAST program;
- St. Michael’s Hospital Crisis Outreach Program (Toronto); and
- St. John’s (Newfoundland) program for individuals with complex mental health needs who have been involved with the criminal justice system.

Appendix 8 provides a summary of these programs.

### *5.6 What are the gaps in services and funding? What strategic improvements are suggested?*

As with short-term acute home care services, there is considerable variation in what is available for clients experiencing an acute mental health episode. Whether crisis response services exist and, if they do, what is included varies widely. Services that are provided

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<sup>38</sup> Reding G & Raphelson M. 1995. Around-The-Clock Mobile Psychiatric Crisis Intervention. *Community Mental Health Journal* 31(2):179-190. As cited in *Review of Best Practices in Mental Health Reform*.

<sup>39</sup> Edwards J, McGorry P & Pennell K. 2000. Models of Early Intervention in Psychosis: An Analysis of Service Approaches. In Birchwood M, Fowler D and Jackson C (Eds.) *Early Intervention in Psychosis: A Guide to Concepts, Evidence and Interventions*. Chichester, UK: Wiley & Sons Ltd.

through the mental health sector are generally less developed and less well funded compared to other health care sectors.

Issues of definition must be resolved. Consideration should be given to the inclusion of addictions under acute community mental health services; regardless of the cause of the acute mental illness episode, the service response should be the same. Given the nature of mental illness and the unique needs of this population, key experts view a focus on acute episodes and a two-week service limit as inappropriate and short-sighted. A focus on maintenance and preventative services through adequate funding is more likely to avert acute episodes. Furthermore, clients with an acute occurrence of mental illness usually have an underlying chronic condition that still requires care once the incident has been stabilized. Removal of services either at the end of two weeks or when the condition is stabilized may result in a relapse, triggering another acute episode. While we recognize the issues of sustainability and available funding, the decision to provide only two weeks of services does not address the downloading of hospital costs to the community and the entitlement to care equivalent to that provided in hospitals.

Unlike patients with physical needs, persons living with a mental illness require a much broader range of community supports and services both inside and outside the health sector to prevent relapse. In considering the provision of services, at a minimum, case management, professional services and medications and medications management should be fully publicly funded. Support services need to be available in the same way and on the same terms as they are for physical/functional conditions whether through home care programs or through community mental health. Because of the special needs and the challenges of treatment compliance with this population, First Ministers need to give consideration to the inclusion of services that are not traditionally publicly funded by home care programs, such as transportation. Many acute mental health services are delivered in the community (e.g. agency offices) and clients who may be resistant to treatment must travel to these sites. Furthermore, because of the high rate of mental illness among the homeless population, housing requires some attention.

First-dollar coverage does not preclude the imposition of user charges, as stated above. Charges or co-payments may be unsuitable for this population since stabilization depends on patient compliance with treatment. Because of the nature of the illness and the side effects of drugs, some clients are resistant to taking their medication. In addition, more so than in other sectors of health care, a higher proportion of people living with a mental illness are on social assistance or are homeless without disposable financial resources. Accordingly, user charges or co-payments may impede compliance.

Existing acute community mental health services are currently provided through mental health programs and not through home care programs. The 2003 Accord and the 2004 plan do not specify that these services be provided through home care. There is some evidence that the provinces and territories believe that home care is the wrong sector to provide this type of care. Although placing acute community mental health care within the home care sector does not artificially compartmentalize physical and mental health needs, the home care sector has less expertise in caring for mental illness. Nevertheless,

home care programs might be in a better position to identify those clients who are experiencing a first episode of a condition. A number of key informants concur with most of the provinces that these services should remain within the sector with the most expertise, namely, the mental health sector. However, community mental health programs should be given a portion of resources targeted for home care to ensure a national standard in acute community mental health.

Although the mental health sector has made strides in improving integration with the primary and acute care sectors, much more needs to be done. Because clients with mental illness also have physical or functional needs, better coordination and integration must exist between the mental health and home care sectors. Traditional home care services should be made available to this population based on need. Innovations and reform should continue to explore better ways of integrating the care of persons living with a mental illness and/or addictions, and these reforms should encompass the spectrum of health care: primary care, home and community care, and acute care. The role of the private sector in assisting with the integration of mentally ill clients into the workplace needs to be encouraged and enhanced.

## **6.0 End-of-Life Care**

### *6.1 What have governments promised?*

The 2003 Accord and the 2004 plan, while instructing Health Ministers to determine a minimum basket of services for end-of-life care, were silent on the definition of end-of-life care. It was agreed in the 2004 plan that first-dollar coverage will be established for a basket of home care services no later than 2006.

Services should include:

- case management;
- nursing;
- palliative-specific pharmaceuticals; and
- personal care.

In addition, to support family members caring for gravely ill relatives, the 2003 Accord indicated that the Government of Canada would supplement home care reforms with a compassionate care benefit through the Employment Insurance Program and job protection through the Canada Labour Code.

### *6.2 What do we mean by end-of-life care?*

In the absence of an Accord definition for end-of-life, other sources were reviewed. Many of these speak of palliative care interchangeably with, and sometimes as distinct from, end-of-life care. The distinction usually focuses on whether palliation can be given to patients who are still under active treatment and not necessarily in imminent danger of death.



The World Health Organization defines palliative care as “an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems.”<sup>40</sup>

A subcommittee of the Senate Standing Committee on Social Affairs, Science and Technology defined palliative care as “care aimed at alleviating suffering – physical, emotional, psychosocial, or spiritual – rather than curing.” Partly because palliative care has been too often associated with cancer, the Subcommittee adopted the term, “quality end-of-life care,” to encompass all end-of-life situations. The new term includes adequate pain and symptom control, appropriate use of life-sustaining treatments, and support for patients and their families.<sup>41</sup>

Health Canada defines palliative care as providing the best quality of life for the critically or terminally ill by ensuring their comfort and dignity. An important objective of palliative care is the relief of pain and other symptoms. Palliative care is planned to meet not only physical needs but also psychological, social, cultural, emotional and spiritual needs of the ill person and his or her family. Family is determined by the dying person and can include friends.<sup>42</sup>

The Canadian Hospice Palliative Care Association, formerly the Canadian Palliative Care Association, defines hospice palliative care as care aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. The association suggests that hospice palliative care is a term that is interchangeable with end-of-life care. Palliative care is seen to be helpful not only when a person is approaching death but also at earlier stages in the illness, and can be combined with treatments aimed at reducing or curing the illness. The goal of care is to meet not only physical needs but also the psychological, social, cultural, emotional and spiritual needs of each person and the family. Along with relief of pain and symptom management, also key are comfort, dignity and best quality of life for the person living with the illness as well as the family. Palliative care services also are seen to help ill, elderly people to live out their remaining time in comfort and dignity.<sup>43</sup>

The Romanow Commission report speaks of palliative care and eligibility as limited to persons with a prognosis of death within six months. Individuals must be referred by a

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<sup>40</sup> World Health Organization. [www.who.int/hiv/topics/palliative/care/en/print.html](http://www.who.int/hiv/topics/palliative/care/en/print.html). Accessed August 7, 2004.

<sup>41</sup> Standing Senate Committee on Social Affairs, Science and Technology. 2000. *Quality End-of-Life Care: The Right of Every Canadian. Final Report*. [www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/updates/rep-e/repfinjun00-e.htm](http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/updates/rep-e/repfinjun00-e.htm). Accessed August 10, 2004.

<sup>42</sup> Health Canada, Palliative Care: Info Sheet for Seniors. [www.hc-sc.gc.ca/seniors-aines/pubs/info\\_sheets/palliative\\_care/pall\\_e.htm](http://www.hc-sc.gc.ca/seniors-aines/pubs/info_sheets/palliative_care/pall_e.htm)

<sup>43</sup> Canadian Hospice Palliative Care Association [www.chpca.net/menu\\_items/faqs.htm#faq\\_what](http://www.chpca.net/menu_items/faqs.htm#faq_what). Accessed August 10, 2004.

physician and services should include pain and symptom relief, case management, professional services, medication management, counseling, and respite care.<sup>44</sup>

CIHI defines an end-of-life client as a “client with a health condition that is not responsive to curative treatment. The intent of this service is to meet the needs of individuals who wish to receive end-of-life care at home. Services are to ease symptoms and provide the best quality of life for clients and their families and not to cure or prolong life.”<sup>45</sup>

Good quality end-of-life care from the patient’s perspective has been determined to include adequate control of pain and symptoms, avoidance of inappropriate prolongation of dying, a sense of control, relieving the burden on family/friends, and strengthening personal relationships.<sup>46</sup>

The federal, provincial and territorial jurisdictions were canvassed for their definitions of end-of-life care. Most provinces with end-of-life care programs referred to palliative care. Symptom management, pain relief, compassion and dignity all appear to be key components in their definitions. Care for the whole family is also a central feature. However, some provinces require a medical determination that patients will die within a defined period, and they require that patients voluntarily relinquish active treatment, while others view palliation as part of ongoing treatment. Appendix 9 includes information gleaned from their responses and their websites.

### 6.2.1 What challenges arise from variations in definitions?

The terms “palliation” and “end-of-life care” can cause confusion. Much of the distinction rests on whether treatment to prolong life or even cure is suitable. “Palliation,” the subject of much research, has been used most extensively in the cancer field. There is concern that it is viewed as care limited to those patients. The term “end-of-life” seems to have been adopted to be more inclusive of all terminal illnesses. There appears to be consensus that recipients of end-of-life care are the terminally ill client and as well as, at a minimum, immediate family and other relatives.

The requirement for a prognosis of death, which many jurisdictions impose, has been identified as problematic. According to recent research, physicians have a tendency to overestimate the time remaining before death and as a result do not make timely arrangements for clients.<sup>47</sup> Moreover, physicians are often reluctant to make a

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<sup>44</sup> Commission on the Future of Health Care in Canada. 2002 *Building on Values: The Future of Health Care in Canada. Final Report*. p. 183.

<sup>45</sup> Canadian Institute for Health Information. 2004. *Development of National Indicators and Reports for Home Care – Phase 2: Project Report*. Draft.

<sup>46</sup> Singer P et al. 1999. Quality end-of-life care: patients’ perspectives. *JAMA* 281:163-68. As cited in Rachlis M. 2004. *Prescription for Excellence: How Innovation is Saving Canada’s Health Care System*. Toronto: Harper Collins.

<sup>47</sup> Christakis N and Lamont E. 2000. Extent and determinants of error in doctors’ prognoses in terminally ill patients: prospective cohort study. *BMJ* 320: 469-473. As reported in Rachlis M. 2004. *Prescription for Excellence*. *ibid*.

determination of end-of-life and a referral to care to ease dying because this is a sign that no hope remains. Many programs require the patient to cease seeking curative treatment, a difficult decision for themselves and their families. Individual variability in disease trajectories due to personal and individual factors further complicates prediction.

### *6.3 What do we know about the need for end-of-life care in Canada?*

More than 220,000 Canadians die each year, 75 per cent of them in hospitals and long-term care facilities. It has been estimated that 160,000 need palliative/ end-of-life care services. Only five to 15 per cent receive integrated and interdisciplinary palliative care. Of those who receive this care, 90 per cent are cancer patients although they represent only 25 per cent of patients who die. Recent polls suggest that while 90 per cent of Canadians wish to remain in their own homes during the final stages of life, only six per cent of informal caregivers feel they can adequately care for their family member without palliative care support.<sup>48 49</sup>

The Quality End-of-Life Coalition in its brief to Commissioner Romanow indicated that there are a range of preferences as to where people want to die, but the availability of alternatives, especially home palliative care, is limited and uneven across Canada. The number of palliative care beds has been cut as a result of health care restructuring, without an offsetting increase in community palliative care. Only four provinces have designated palliative care as a core service under the provincial health plan. Other provinces include this type of care under home care or other health programs, which exposes it to budget cutbacks. Palliative care programs rely disproportionately on charitable giving and informal caregiving. There are insufficient community supports and training for family members, as well as trained health care professionals to meet end-of-life care needs. The Coalition states that Canada has only 160 palliative care physicians; only 12 of the 142 nursing schools offer palliative care training and not all medical schools offer training in this area.<sup>50 51</sup>

Services normally provided in palliative care include:

- pain management;
- symptom management (e.g. loss of appetite, nausea, weakness, breathing difficulty, bowel and bladder problems, and confusion.);
- social, psychological, emotional and spiritual support (focus on the whole person); and
- caregiver support and respite.

Palliative care is usually provided by a multidisciplinary team of professionals and non-professionals and is determined by the needs of the ill person and his/her family. It can

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<sup>48</sup> Standing Senate Committee on Social Affairs, Science and Technology. 2000. *ibid.*

<sup>49</sup> Canadian Hospice Palliative Care Association, Fact Sheet: Hospice Palliative Care in Canada.

<sup>50</sup> The Quality End-of-Life Coalition (23 Stakeholder Organizations) Brief To Roy Romanow, Commissioner, Future Of Health Care In Canada. April 30, 2002.

<sup>51</sup> Canadian Hospice Palliative Care Association, Fact Sheet: Hospice Palliative Care in Canada.

include nurses and a physician with specialized palliative care skills, the family physician, a social worker, a spiritual counselor and a pharmacist. Other health professionals such as nutritionists, physiotherapists, occupational therapists and home support workers may be added to the team as needed. Volunteers can also play an important role in palliative care, providing support services such as companionship, relief for the caregiver, and transportation.

Palliative care is offered in a variety of places—at home, in long-term facilities, in hospitals, and occasionally in hospices. Canada has only a few residential hospices, where care is provided in a facility with a home-like setting.<sup>52</sup>

Although the vast majority of Canadians indicate that they would prefer to die at home, and family members want to provide care to their ill relation, the lack of job and income protection for family caregivers and lack of home care services have made this difficult to achieve. According to the Conference Board of Canada, 48 per cent of family caregivers indicated that it was difficult to balance personal and job responsibilities in providing care for a family member. The hidden costs of family caregiving include a great deal of stress in juggling roles, a lack of sleep, and minor health problems.<sup>53</sup> The most significant indicator of caregiving stress is the lack of choice in taking on this role.<sup>54</sup>

A national survey done for Health Canada<sup>55</sup> indicates that approximately four per cent of adult Canadians (933,000 individuals) were providing care to a relative in 2002. The care responsibility is not evenly distributed across the population. Seventy-seven per cent of family caregivers are women and typically older (70 per cent are 45 years of age or older). A little more than 20 per cent are employed full-time and approximately the same number are employed part-time or self-employed. Although caregivers can be found in all income groups, two-thirds report a household income below the national average (\$45,000).

One-quarter of caregivers indicated that they are in their roles because of a lack of home care services and one-third indicates that no one else is available to provide the care. Impacts on employment are reported by more than one in four caregivers. Leaving a job entirely is disproportionately reported by women. Added to this financial burden are the out-of-pocket costs most are faced with to provide care to their family member. Most common expenses include transportation, prescription and non-prescription drugs, medical supplies and equipment.

Caregivers indicated a strong interest in more workplace supports to balance the demands on their time. A little over 40 per cent would like flexible work hours and a similar

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<sup>52</sup> Health Canada. [www.hc-sc.gc.ca/seniors-aines/pubs/info\\_sheets/palliative\\_care/pall\\_e.htm](http://www.hc-sc.gc.ca/seniors-aines/pubs/info_sheets/palliative_care/pall_e.htm) Accessed August 12, 2004.

<sup>53</sup> Conference Board of Canada. 1999. *Caring about Caregiving: The Eldercare Responsibilities of Canadian Workers and the Impact on Employers*.

<sup>54</sup> Decima Research. 2002. *National Profile of Family Caregivers in Canada - 2002*. Final Report prepared for Health Canada.

<sup>55</sup> Decima Research. 2002. *National Profile of Family Caregivers in Canada - 2002*. *ibid*.

proportion would like to see short-term job and income protection through the Employment Insurance (EI) program.

#### 6.4 What services do the jurisdictions currently provide?

While most provinces and territories indicate that they provide some measure of palliative care, the type, volume and regional availability of services provided vary considerably. Because some provinces do not have formal end-of-life programs, residents are often unaware of services. Who pays for palliative care largely depends on whether the client is in hospital or at home. Palliative care provided in hospital is usually paid by provincial health plans where the costs of care, drugs, supplies and equipment are covered. Residents in long-term care facilities often have to pay part of the costs of palliative care, with costs varying among facilities.

Eligibility of home palliative/end-of-life care often requires a physician referral and a prognosis of death within a set time frame, usually six months. In some jurisdictions, clients must declare that they are no longer seeking curative treatment. Provinces with formal programs pay for nursing, physician services, rehabilitation therapies, personal support, some requiring co-payments. Provincial home palliative care programs may place limits on the amount of professional and personal support services paid for publicly. The coverage of drugs and equipment used at home vary from fully publicly funded, partially publicly funded, funded by government as the payer of last resort, or not funded. There is usually no charge for bereavement support, which is often provided as part of palliative care services offered in hospitals or by non-profit or volunteer organizations in the community.

Appendix 10 provides a summary of jurisdictional programs. Not all jurisdictions responded to our survey. Some descriptions are based on provincial/territorial websites or other reports.<sup>56 57</sup>

##### 6.4.1 Compassionate Care Benefits

On January 4, 2004, Canadians became eligible for the new federal compassionate care benefits.<sup>58</sup> Bill C-28, the *Budget Implementation Act, 2003* amended the *Employment Insurance Act* and the *Canada Labour Code*. The benefit will provide a maximum of six weeks of employment insurance for employees who need to be absent from work to provide care or support for a family member who is gravely ill with a significant risk of death (within 26 weeks). The family member may live in or outside Canada. A medical certificate is required to testify that the ill family member needs this care and support and is at significant risk of death within the 26 weeks. Some critics have suggested that family members may be unwilling to ask a physician to make such a determination and

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<sup>56</sup> Health Canada. *ibid.*

<sup>57</sup> Canadian Hospice Palliative Care Association. [www.chpca.net/menu\\_items/faqs.htm#faq\\_whopays](http://www.chpca.net/menu_items/faqs.htm#faq_whopays).

<sup>58</sup> Human Resources Development Canada, *Compassionate Care Benefits*. [www.hrdc-drhc.gc.ca/ae-ei/menu/faq/compassionate\\_care.html#Definition](http://www.hrdc-drhc.gc.ca/ae-ei/menu/faq/compassionate_care.html#Definition). Accessed January 14, 2004.

that family physicians may be unwilling themselves to make such a declaration. In contrast, Quebec's *An Act respecting labour standards* only requires, in the instance of a sick child, that the child has "a serious and potentially mortal illness" to qualify for palliative care leave.<sup>59</sup>

The Compassionate Care Leave benefit defines family members as:

- the individual's child or the child of his/her spouse or common-law partner (person living in a conjugal relationship with the individual for at least a year);
- the individual's wife/husband or common-law partner;
- individual's father/mother; or
- the wife of the individual's father/ the husband of the individual's mother;
- the common-law partner of individual's father/mother.

These benefits will be paid to all workers who are entitled to Employment Insurance (EI) Benefits, including those who are unemployed and on employment insurance. To be eligible for the benefits, individuals must demonstrate that their regular weekly earnings from work have decreased by more than 40 per cent and that they have accumulated 600 insured hours in the last 52 weeks (similar to other EI benefits) or since the start of the last claim. Although individuals may break up their six week benefit period, the benefits must be taken within 26 weeks of their commencement. This requires the caregiver to judge which weeks would be most beneficial to claim.

The basic benefit is 55 per cent of the individual's average insured earnings and the maximum benefit is \$413 weekly. Higher benefit rates are available for low-income families with children (income less than \$25,921). Individuals receiving compassionate care benefits are only able to earn \$50 or 25 per cent of their weekly benefits, whichever is higher. Money earned above the limit will be deducted dollar for dollar from the benefits. The \$50 or 25 per cent of weekly benefits can be from employment wages/commission, workers' compensation, group insurance income for sickness or loss of income, accident insurance, and pension income. Employers are allowed to include compassionate care benefit payments in their supplementary unemployment benefit and these payments will not be deducted from EI payments to a claimant.

The first two weeks of caring for the family member must be unpaid; in effect, this means that earnings from vacation pay or severance pay will be deducted from the actual benefits. If the benefit is being shared amongst a number of family members, only one member is required to wait the two weeks. This stipulation serves as a form of deductible. Payment of benefits is likely to take approximately 28 days which means that the individual will be without income for almost a month. Benefits end either when the six weeks of EI have been paid, the ill family member dies or no longer requires care, or the 26 week period has expired.

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<sup>59</sup> Human Resource Professionals Association of Ontario (HRPAO). New compassionate care leave benefits program introduced. December 2, 2003. [www.hrpaoo.org/Knowledge\\_Centre/kc\\_s12020306.asp](http://www.hrpaoo.org/Knowledge_Centre/kc_s12020306.asp). Accessed January 3, 2004.

Finally, amendments have been made to the Canada Labour Code to establish an entitlement to a period of leave of up to eight weeks (six weeks of benefits plus the two-week waiting period) with job protection within a 26-week period for the purposes of providing compassionate care. This means that federally regulated employees taking advantage of the benefits will not risk losing their jobs and are entitled to the same rights regarding seniority, pension, health and disability benefits. Nine of 13 provincial/territorial jurisdictions have followed suit and amended their labour legislation to provide job protection.

### *6.5 What do Canadian jurisdictions currently do well?*

End-of-life care received greater attention with the release in June 2000 of the Senate Subcommittee report, *Quality End-of-Life Care: The Right of Every Canadian*. Another important development was the establishment in June 2001 of the federal Secretariat on Palliative and End-of-Life Care to act as a focal point on end-of-life issues and to coordinate the development of a national strategy on end-of-life care. Health Canada has since established five working groups to address the following priorities: best practices and quality care; education for formal caregivers; public information and awareness; research; and surveillance. Care needs of certain specific groups of Canadians such as immigrant communities, Aboriginal peoples, and people with disabilities may also be addressed.<sup>60 61</sup>

A number of jurisdictions have put in place innovative end-of-life care programs. The best practice elements of these projects include:

- a single-entry access;
- common patient chart/records;
- multidisciplinary teams;
- 24/7 coverage and/or dedicated phone lines;
- access to outpatient clinics, day hospitals and hospice care;
- evidence-based assessment tools, common standards for care, and practice guidelines;
- ethnic-spiritual sensitivity;
- comprehensive service provision (professional, medical equipment/supplies, drugs, personal support, homemaking, respite, social and bereavement support).

Telehome care offers promise for rural and remote communities.

Examples of innovative programs include:

- Edmonton Regional Palliative Care Program;

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<sup>60</sup> Health Canada, Palliative Care. [www.hc-sc.gc.ca/english/care/palliative\\_secretariat.html](http://www.hc-sc.gc.ca/english/care/palliative_secretariat.html).

<sup>61</sup> Health Canada, Secretariat on Palliative and End-of-life Care News. [www.hc-sc.gc.ca/english/care/palliative\\_secnews.html](http://www.hc-sc.gc.ca/english/care/palliative_secnews.html).

- Toronto Hospice Palliative Care Network Project;
- Palliative Care Integration Project Southeastern Ontario;
- Ottawa's Mission Union Hospice for the Homeless;
- Montreal's Toward a Continuum in Care and Services for Terminally Ill Adult Users; and
- Nova-Scotia/PEI Rural Palliative Home Care Project.

Descriptions of these projects may be found in Appendix 11.

*6.6 What are the gaps in services and funding? What strategic improvements are suggested?*

End-of-life care programs are largely unavailable across the country, inconsistently available within jurisdictions, more readily available for some patient groups than others, and not well known by Canadians. To begin with, consistent terms and definitions are required, to ensure that all Canadians understand their entitlements. It may be more suitable to reserve palliation for care provided to patients with conditions for which there is no expected recovery and the determination of time of death is uncertain and dependent on other variables. Included in this category would be conditions such as amyotrophic lateral sclerosis (ALS) and Parkinson's disease. The requirement by some jurisdictions to predict the likely time of death creates practical and emotional difficulties for physicians, patients, and their caregivers. Given that the First Ministers' 2004 plan places no limit on the amount of service, it may be more suitable that eligibility criteria not include a likely period to death. In addition to case management, nursing, palliative-specific drugs and personal care, entitlements should also include the cost of equipment and supplies, on the premise that these costs would be covered if the patient was hospitalized for end-of-life care.

The federal compassionate care benefit is a positive step. However, these benefits are not available to the unemployed or self-employed, who are ineligible for EI. As a result, women will likely comprise a disproportionate component of those ineligible for the compassionate care benefit, although they are more likely to be the caregiver. Furthermore, the program offers no support to individuals who must interrupt their employment to care for an ill family member who is not at risk of dying but who has a serious illness or has had a debilitating procedure. Because applications must be done either on-line or in person at the local HRDC office, persons in rural or remote areas are at a disadvantage if they do not have Internet access.

No doubt anticipating criticism that the benefit period is too short, the federal government has stated that the six-week benefit was set based on medical information, best practices in the public and private sectors, and the fact that most Canadians who have taken time off from work to provide care or assistance to a gravely ill family member did so for six weeks or less. This latter fact may be more a reflection of family members' inability to afford additional time without income or their fear for loss of job and benefits security,



rather than the fact that further time for care was no longer needed. In addition, as indicated above, the length of the benefit assumes that individuals and their physicians are able to predict when the ill family member is likely to die and therefore when the family caregiver should take time away from work.

The sustainability of the health care system depends in part on the participation of unpaid caregivers. The compassionate care benefit should be viewed as a first step toward the development of a comprehensive package of supports for caregivers. The program should be reviewed to provide benefits to all Canadians, and research should be conducted to evaluate the sufficiency of the six-week benefit period.

## **7.0 Reporting**

### *7.1 What have governments promised?*

In the 2003 Accord, First Ministers agreed to report to their citizens on home care, starting in 2004 – to inform them of current programs, service levels, outcomes and spending as well as on progress achieved. They further agreed to use comparable indicators and to develop the necessary data infrastructure for these reports.

In the 2004 plan, First Ministers agreed that each jurisdiction will develop a plan for the staged implementation of home care services and report annually to its citizens on this implementation. They further agreed to task their Health Ministers to explore next steps to fulfill the home care commitment and report to First Ministers by December 31, 2006.

### *7.2 What is currently happening?*

#### *7.2.1 Challenges in home care reporting*

Because home care programs have developed in response to local needs, available resources, and in the absence of national standards, they vary considerably across federal, provincial and territorial jurisdictions. Challenges in national monitoring and reporting on home care have been confounded by other factors, which include:

- lack of a common definition for home care and common services in each province;
- lack of comparable assessment and measurement tools;
- a mix of paper and electronic records;
- different financial capabilities to invest in information infrastructure;
- inability to exchange information across different systems; and
- lack of a common protocol for reporting home care information.

The problem of reporting home care information at a national level is further complicated by historical reporting requirements and Canada's ability to provide comparative

information on an international level. Home care data collected at the national level and reported in the National Health Expenditures (NHEX) uses the OECD definition of home care and includes home care expenditures for care provided by health practitioners. However, home support services, which have historically been part of provincial/territorial home care programs, are considered outside of the OECD and NHEX definitions because they are not provided by health practitioners.<sup>62</sup> As a result, a critical portion of what policy makers consider to be home care in Canada – services that prevent or delay institutionalization – is not systematically captured. Moreover, some provinces do not separate out social support expenditures from home care health expenditures, while others do. The current approach includes only professionally-provided care and probably underestimates public home care expenditures in Canada. Nevertheless, the ability to continue collecting information in this way is important to allow historical and international comparisons on health expenditures.

### *7.2.2 First Ministers' reporting*

In September 2000, the First Ministers agreed to provide health care reports on 14 areas to Canadians in September 2002 and again in November 2004. A Performance Indicators Reporting Committee (PIRC) was established to develop the framework and to populate the 14 areas. Sixty-seven common indicators were developed for the 14 areas, generally grouped as health status, health outcomes and quality of health care services. Each of the provinces, territories and the federal government is responsible for publishing a separate report containing information on the 14 indicator areas. Reports were released by most jurisdictions in September 2002. Although data were not available for all jurisdictions and all indicators, the reports offered a snapshot of what was happening within each province and territory in Canada.

Four of the indicators developed relate to home and community-based services: patient satisfaction with community-based services received (Indicator 9d); home care admissions and home care admissions age 75+ (Indicators 12a-b); utilization of home care services (Indicator 12c); and ambulatory care sensitive conditions (Indicator 12d). However, not all jurisdictions could report on home care admissions, home care admissions age 75+, or home care utilization, nor on the 2003 Accord home care areas of short-term acute home care, acute community mental health, and end-of-life care.<sup>63 64</sup>

Since the 2002 report, the Performance Reporting Technical Working Group, which replaced the PIRC and which reports to the FPT Advisory Committee on Governance and Accountability, issued a report documenting further work on the performance indicators. The former indicators 12a-b and 12c listed above are no longer in the new list of 70 indicators. An indicator on patient perceived quality of community-based care was

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<sup>62</sup> Ballinger G, Zhang J, Hicks V. 2003. *Monitoring the Feasibility of Reporting Home Care Estimates in National Health Expenditures*. (updated by C. Gyiorfi-Dyke). Canadian Institute for Health Information.

<sup>63</sup> Canadian Institute for Health Information. Performance Indicators Reporting Committee: General Briefing Note. [http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=pirc\\_about\\_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=pirc_about_e).

<sup>64</sup> Health Canada. 2002. *Healthy Canadians: A Federal Report on Comparable Health Indicators, 2002*. [www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/accountability/annex1.html](http://www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/accountability/annex1.html).

added.<sup>65</sup> Prior to its publication, the First Ministers announced that their November 2004 report would be based on the earlier PIRC indicators.

### 7.2.3 Indicator development

The Health Information Roadmap Initiative – a collaborative effort among various stakeholders including the Canadian Institute for Health Information (CIHI), Statistics Canada, Health Canada, provincial/territorial health departments, plus others, was a four-year plan to strengthen Canada’s health information system. While good information exists on hospitals, data on other delivery options are quite basic, incomplete or non-existent.<sup>66</sup> With money from the Health Transition Fund and the Roadmap Initiative, CIHI has undertaken a number of initiatives to develop national priority indicators and reports for home care.<sup>67</sup> Specifically, the goals of the project were to develop indicators that would allow provinces and territories as well as health regions within them to compare access, outcomes, the use of resources, and client and system characteristics in home care.

In phase 1, 16 indicators were developed and defined using existing information to allow provinces and territories to monitor and compare their performances in acute care substitution, rehabilitation, end-of-life care, maintenance and long-term supportive care, and support for informal caregivers. Testing of these indicators highlighted a number of challenges and pointed to the need for a standardized data source in order to collect standard home care information. In 2002-03 CIHI tested the feasibility of collecting the data required to compile the indicators in six health regions (Newfoundland, Manitoba, Saskatchewan, Alberta, British Columbia, and Yukon).

The results from the pilot project underscored the differences in home care programs, some of the difficulties in collecting standardized data, as well as lessons learned. These are some of the many findings:

- Not all home care services are provided in the home; some are provided in communities or over the telephone. As a result data must capture services that enable people to remain at home.
- Important data are excluded or not collected because some services that are considered home care services in certain jurisdictions are provided by other programs in other jurisdictions.
- When a client becomes a home care client is determined differently across the jurisdictions, making it difficult to compare data on wait times and admission

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<sup>65</sup> Advisory Committee on Governance and Accountability. 2004. *Comparable Health Indicators in November 2004* (as approved by the Conference of Deputy Ministers of Health).

<sup>66</sup> Health Information Roadmap Initiative. *Questions and Answers*.  
[http://secure.cihi.ca/cihiweb/en/downloads/profile\\_roadmap\\_e\\_FAQ.pdf](http://secure.cihi.ca/cihiweb/en/downloads/profile_roadmap_e_FAQ.pdf).

<sup>67</sup> Canadian Institute for Health Information. 2004. *Development of National Indicators and Reports for Home Care – Phase 2: Project Report*.

rates across the country. Further consultations with key stakeholders are required to address this issue.

- Variations in discharge procedures and dates can impact on admission rates. In some jurisdictions clients with gaps in home care services may be considered new admissions and in others not. To ensure comparability, CIHI proposes to collect the dates of the first and last service received as well as the program's administrative dates of admission and discharge.
- Home and community care services to First Nations people and Inuit are funded by the First Nations and Inuit Health Branch of Health Canada, but some of these services may be delivered through provincial/regional home and community care programs. There is potential for duplicate data collection and double counting. CIHI will work with Health Canada to resolve these issues.
- Much of the data collected in the pilot are similar to those already routinely collected by jurisdictions. To reduce duplication, data collection for national comparison should flow from information routinely collected through the process of care. This would require standardization through the use of common or comparable clinical assessment tools. CIHI is collaborating with the InterRai Corporation on such a tool (the RAI-HC©).
- The burden of collecting the minimum data defined in the pilot project was considered not justifiable for certain client groups. This largely included those clients who had few service needs, such as acute care substitution clients who may only receive one or two visits. It was clear that the benefits of the data must outweigh the costs of collecting it. InterRAI has been developing a triage system, InterRAI-CHIP (Community and Hospital Intake Profile) in Ontario. One of its purposes is to provide a basic assessment of short-term service clients (rehabilitation and medical) who would *not* be receiving any additional assessment at a later stage.<sup>68</sup>
- The need for data standards to ensure reliable and valid information on home care was reinforced through the pilot. The uptake of a common standardized assessment tool such as the RAI-HC©, along with a comprehensive data quality strategy mounted by CIHI to train and support jurisdictions on a continuing basis in the collection of data are suggested.
- Unique client identifiers were recognized as critical for accurate tracking of patients across episodes of care, and across services and service providers. Some jurisdictions have already introduced the identifier to be used for every episode of care.
- Electronic real-time data collection at the point of care results in improved data quality and timely production of reports and outcomes. However, switching from paper to electronic data collection requires significant investments in people and

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<sup>68</sup> Personal communication. 2004. John Hirdes, Professor, Department of Health Studies and Gerontology, University of Waterloo and Scientific Director, Homewood Research Institute.

infrastructure. Because jurisdictions have varying financial resources to make this transition, CIHI will allow for both types of data collection methods.

- While the types of home care clients across the country are likely to be similar, service offerings vary considerably. As a result, the high level distinction between client groups should be based on the characteristics and needs of clients rather than the types or level of services provided.
- The amount, quality and comparability of service utilization data is likely to be affected by the service delivery models in place. Although there is a need to account for services that are publicly funded, private sector provision discourages the disclosure of detailed business information.

At the moment, the indicators cannot be populated on a national basis because the required common data sets do not exist in all jurisdictions. However, the indicators have established a data standard towards which each jurisdiction can strive to collect the necessary information. Other elements that will greatly contribute to the reporting on home care will be a common/comparable clinical assessment tool and a home care reporting system that will allow jurisdictions to participate in the reporting of the indicators.

#### *7.2.4 Progress on a common/comparable assessment tool*

Canadian jurisdictions currently use a variety of assessment tools, many of which do not allow comparison of data elements. See Appendix 12 for a review of assessment tools and formats for each jurisdiction. Common or, at a minimum, comparable assessment tools would greatly improve not only quality of care but also provide data for providing information on client demographics and social and clinical characteristics. Through a comprehensive consultation process and a one-day meeting in December 2003, key stakeholders discussed the vision for a Canadian home care reporting system (HCRS). Two key messages that emerged from the meeting were: 1) the use of a standardized clinical assessment tool will improve the quality and usefulness of indicators, and 2) to reduce the administrative burden for providers, data for national reporting should be a by-product of the process of care.

As of 2004, Nova Scotia, Ontario, British Columbia and the Yukon are in the process of implementing or have implemented the assessment tool, RAI-HC©. Newfoundland, Manitoba, Saskatchewan, and Alberta are exploring the feasibility of adopting the RAI-HC©. InterRAI is currently conducting research and working on developing assessment tools for short-term acute home care and end-of-life clients.

Although Quebec and Prince Edward Island are using other tools, on the whole the information collected is comparable to that collected by the RAI-HC©. The consultations revealed that many jurisdictions have few financial, human and technical resources to automate data collection at this time.<sup>69</sup>

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<sup>69</sup> CIHI. 2004. *ibid.*

### *7.2.5 Development of a home care reporting system*

The Home Care Reporting System (HCRS) development project was officially launched by CIHI in April 2004. It is a two-year initiative to design, build and test a reporting system for home care. It will provide standard data definitions and descriptions that will assist jurisdictions to collect data according to these standards and will allow all provinces and territories to participate in national reporting of the Roadmap Indicators described above. Along with the indicators developed through the Roadmap Initiative, it will incorporate the RAI-HC© tool; the indicator specifications have been modified to allow them to be directly populated from the RAI-HC©. HCRS will also be designed to accept information from jurisdictions using tools comparable to the RAI-HC©. Ultimately the reporting system will provide longitudinal and cross-sectional statistical reports and analysis with respect to clients who receive publicly funded home care. Data collection for the HCRS will begin with BC in 2005. Consultations will be held the same year with other interested jurisdictions for further implementation. Because of the difficulties in implementing business processes and information systems for home care, CIHI has designed the HCRS to accommodate an incremental and phased approach to implementation.

### *7.3 What are the gaps in progress on reporting? What strategic improvements are suggested?*

The development of performance indicators and a reporting system is a long and arduous process that requires continuous consultation and refinement with those involved. Through CIHI's leadership, considerable progress has been made in identifying and standardizing home care indicators; in assisting provinces to adopt common assessment tools; and in providing the training and support to those jurisdictions that are and will be participating in implementing the HCRS. The development of a reporting system that can accommodate information from non-RAI-HC© tools, and that adopts a phased-in approach, will greatly assist provinces/territories that use varying assessment tools and have different information technology capabilities.

CIHI should be encouraged to continue its work with all jurisdictions, especially on the adoption of common or comparable clinical assessment tools. The federal government should provide the financial assistance to provinces and territories to help them develop and implement electronic information systems and the business processes required to support them.

The various monitoring and reporting exercises represent improvements in the accountability of governments and the health care system to the public. However, there is little indication as to whether these exercises address what citizens want to know or find useful. The recommendation of the Canadian Policy Research Network to "move beyond the reliance on public reporting of performance information as a primary accountability

mechanism and start to experiment with other mechanisms such as citizen engagement processes” is advice that has merit.<sup>70</sup>

## **8.0 Challenges and Opportunities**

### *8.1 Health human resources*

With the increasing demand for and complexity of home care services, the pressure on human resources in this sector has been growing. Of concern are a number of issues documented by a national study.<sup>71</sup> Compared with the institutional sector of health care, home care has difficulty attracting and retaining workers. Shortages are most acute in rural and remote areas. The lack of public and government recognition of the importance of these workers has eroded the attractiveness of the work. Funding levels for home care have not kept up with demand, which has had an effect on the stability of employment, compensation, and has resulted in a change in the nature of the work. Lower wages and benefits compared with the acute care sector and differential wages within the home care sector act as disincentives for people to enter this field of work. With overall shortages in some of the professions such as nursing, the home care sector tends to be the less preferred choice for employment. Lack of training opportunities and suitable education models will further erode the supply

The sector attracts and is dominated by female workers, limiting the potential supply of workers. Most formal providers are over the age of 40. With a shortage of professional providers, notably nurses, there has been an increase in the use of home support workers in institutional sectors, further reducing the potential supply for the home care sector. The overall shortage of workers has increased the weight on family and unpaid caregiving. With a shift away from the preventive and maintenance functions of home care to acute home care, the complexity of the work is perceived to have increased. The use of lower skilled workers has prompted a call for more training specific to the role that providers must carry out. There is some concern about the overlap in functions.

The home as a workplace brings with it unique challenges in that there are varying living and hence working standards. As a result, safety and quality issues are variable and receive less scrutiny; i.e. the home is less visible and can hide abuse of both clients and workers.

### *8.2 “Medicalization” of home care and discontinuity of care*

The Accord has given prominence to many pressing issues with respect to home care. However, the separation of acute from chronic home care, the emphasis on hospital

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<sup>70</sup> Fooks C & Maslove L. 2004. *Rhetoric, Fallacy or Dream? Examining the Accountability of Canadian Health Care to Citizens*. Report of the Health Network, Canadian Policy Research Network. March 2004, p. 3.

<sup>71</sup> Canadian Home Care Human Resources Study. 2003. *Synthesis Report*. Government of Canada.

diversion, and the resultant marginalization of the prevention and maintenance functions of home care, have stimulated the “medicalizing” of home care, creating silos within silos of care and potentially increasing discontinuity in care. This goes against the growing wisdom about health care – the importance of prevention and the integration of care along the full continuum of care for improving health status, the quality of care, and the financial sustainability of the health system. Concern has been expressed by a number of key informants and stakeholder groups that the growth of, and emphasis on short-term acute home care services have led to a cannibalization of home care programs, reducing the amount of funding and services available for chronic care clients.

### *8.3 Technology, information platforms and electronic health records*

The home care sector is a growth sector faced with increasing demands. However, the use of technology and the variant capabilities across the country and within jurisdictions are having an impact not only on the accountability within the sector but also on the quality of care. Many jurisdictions are still using paper records that result in multiple assessments and difficulties in coordinating care across providers and provider organizations. The use of technology and telehomecare have the potential for increasing the efficient use of resources, particularly human resources, and accessibility to care in rural and remote areas. The development and implementation of electronic health records and unique identifiers will greatly improve the continuity and quality of care. Privacy concerns must be addressed.

### *8.4 New models of care*

Canadians as well as health care professionals and support workers want seamless, quality care. However, current models of delivery impede and to some extent discourage integrated and coordinated care. First Ministers have recognized this through the promotion of primary health care reform, which focuses on multidisciplinary teams, judicious use of generalists versus specialists, financial incentives, 24/7 coverage, common patient records, and the prevention, health promotion function of health care. These factors need to be supplemented with an alignment of goals and agreements across sectors of care to facilitate communications, the sharing of information, and the navigation of patients across the continuum of care. Comprehensive clinical information systems through data and tracking can enhance the care for individuals and alert communities to growing population health issues. With an increase in chronic conditions, the health care system needs to be less reactive and more proactive in keeping people healthy. Considerable work has been done in a number of jurisdictions on the chronic care model to guide system change.<sup>72 73</sup>

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<sup>72</sup> Dixon J, Lewis R, Rosen R, Finlayson B, Gray D. 2004. Can the NHS learn from US managed care organizations? *BMJ* 328: 220-2.

<sup>73</sup> Improving Chronic Illness Care (ICIC). The Chronic Care Model. [www.improvingchroniccare.org/change/model/components.html](http://www.improvingchroniccare.org/change/model/components.html).



## 9.0 Overall Recommendations

After reviewing the available information collated above and the advice of key informants, the Health Council of Canada Working Group on Home Care has the following recommendations for First Ministers as they proceed to implement the 2004 plan and consider future improvements to home care and health care for Canadians:

- Greater clarity of definitions, eligibility criteria, and functions of short-term acute home care, acute community mental health, and end-of-life care is needed.
  - “Short-term acute home care” should include not only post-hospital care but also care for acute episodes to prevent hospitalization or placement in a residential facility.
  - “Acute community mental health home care” should be defined broadly enough to include clients with substance abuse problems and concurrent disorders.
  - There needs to be clarity around the terms “end-of-life” and “palliative” care. Physicians may be reluctant to predict death with the required precision of six months and caregivers are faced with the uncertainty of when to apply for compassionate care benefits. The requirement for a diagnosis of death within six months should be reviewed to determine if it creates a significant barrier to uptake of compassionate care benefits; flexibility should be considered.
- First Ministers need to ensure that the basket of services for each home care target program is considered to be a minimum standard. Jurisdictions should be encouraged to include those services that would not only be a substitute for comprehensive, universal, and accessible institutional care, but are also tailored for each targeted population. For example:
  - The basket of services for short-term acute home care should be reviewed consistently across jurisdictions to consider the inclusion of treatments and services, such as rehabilitation therapies, which can provide substantive, long-term benefit.
  - The basket of services for acute community mental health should take into account the unique nature of mental illness and addictions, and include such services as the cost of medications, and transportation, and a focus on maintenance and prevention functions which are more likely to avert acute episodes of chronic conditions; and
  - Supplies and equipment are often a costly component of end-of-life care and the cost of including them in the basket of services, along with the implications of not including them, should be thoroughly examined.
- Setting service limits for the core basket of services not be cost-efficient for the health care system. Rather, services should continue for as long as they are

needed to prevent a relapse. Clients who are stabilized but still require some care and support should be linked and transitioned into other programs.

- Governments should be encouraged to provide full-dollar coverage to ensure universality across Canada; clients should be certain that they will receive comparable services whether they are at home or in hospital. Full-dollar coverage most closely compares to the coverage currently provided for hospital care. User fees and co-payments are a possibility with first-dollar coverage.
- Acute community mental health services should be delivered through the mental health sector, where the expertise lies, with better integration and coordination with the home care sector. Imbalances in the way funds are allocated between these sectors should be addressed.
- Compassionate care benefits are provided through the Employment Insurance program. This mechanism leaves a gap for those not eligible for EI. The federal government should explore ways to also provide compassionate care benefits to those Canadians not working within the coverage of the Employment Insurance program.
- CIHI is encouraged to continue its work with all jurisdictions with respect to the development of data standards, performance indicators and the adoption of common or comparable clinical assessment tools and to implement nationwide data collection.
- The federal government supports the development of electronic client record systems in the provinces and territories through such publicly funded bodies such as Canada Health Infoway. Consideration must be given to providing similar support for the collection and reporting of home care information.
- All jurisdictions should build upon current best practices and technology in expanding services to rural and remote areas.
- All jurisdictions should explore new training models and a human resource strategy to ensure the mix of appropriate personnel required to provide quality care.
- All jurisdictions should recognize through funding the importance and effectiveness of the preventive and maintenance functions of home care in promoting health, maintaining independence, and preventing deterioration of health status, as well as advancing the sustainability of the health care system.
- The First Ministers should expand and enhance the range of accountability mechanisms and where possible, encourage increased citizen engagement with respect to home health care.
- Jurisdictions must explore and develop new models of care that focus on the needs of the patients rather than the organization of providers and the administrative needs of government, and take into account community and social health issues.

- All jurisdictions should explore the role of and the need to support informal caregivers in the home care context.
- All jurisdictions should consider integrating community and social services within the sphere of home care.
- All jurisdictions should consider how chronic disease management fits within home care.
- The Ministers of Health and Federal/Provincial/Territorial advisory committees are encouraged to explore greater integration of the various elements of the 2003 and 2004 agreements on health care renewal. Examples could include, but are not limited to, the integration of primary health care reforms with home care reforms, or the integration of action on health human resources (such as inter-professional education, workplace health, and health human resources planning) with other elements of accords.
- Funding agencies should be encouraged to promote and support research into home health services, including cost effectiveness.

## **Appendix 1**

### **Questionnaire to Federal, Provincial, Territorial Jurisdictions**

**HEALTH COUNCIL OF CANADA  
WORKING GROUP ON HOME CARE**

The Working Group on Home Care is grateful and appreciative to provinces for taking the time to respond to its questions. In the interest of not creating undue workload for provincial/territorial staff, should the information to answer any of the questions listed below already exist, please either forward the document or provide the reference for the document. If it is easier to provide answers verbally, a telephone interview can be scheduled at a time convenient for you.

Should you need any clarification of the questions, please contact Pat Baranek by phone or by email (contact information listed below). For any questions about the Health Council, please contact Cathy Fooks, Executive Director, by phone at (416) 481-7397, x 2398 or by email at [cfooks@hcc-ccs.ca](mailto:cfooks@hcc-ccs.ca).

**Please forward written responses to the questions, relevant documents and references either electronically or by mail by Friday, July 30, 2004 to:**

**Patricia M. Baranek  
106 Bedford Rd.  
Toronto, Ontario  
M5R 2K2**

**Tel: (416) 921-5973  
Email: [pat.baranek@utoronto.ca](mailto:pat.baranek@utoronto.ca)**

**I. DESCRIPTION OF HOME CARE PROGRAM**

1. What is the mandate/mission of the home care program in your jurisdiction? How does your jurisdiction define home care?
  
2. Is the summary of your jurisdiction's home care program and its services as outlined in the 2003 Canadian Home Care Association's report, *Portraits of Home Care: A Picture of Progress and Innovation*, correct and up to date? If not, please describe what is incorrect or needs to be updated.

**II. 2003 ACCORD HOME CARE ITEMS**

**1. Minimum Basket of Home Care Services**

- a. In defining the minimum basket of home care services, what do/did your Jurisdiction perceive as the challenges/barriers to reaching a consensus? What will it take to reach consensus?
  
- b. In terms of the core services suggested in the Accord (nursing/professional services, pharmaceuticals and medical equipment/supplies, support for personal care needs, and assessment of client needs and case management) to be included in a basket of services for the three Accord home care elements (short-term acute home care, acute community mental health home care, and end-of-life care) by 2006, what is your Jurisdiction's position? Will your jurisdiction be able to provide these services by 2006? If not, when will it be in a position to provide them?

**2. Short-term Acute Home Care**

CIHI defines an acute home care client as a “client with acute health or post surgical condition(s) with clearly identified and predictable outcomes or expected recovery.”

- a. How does your jurisdiction define short-term acute home care? Does your jurisdiction agree with the above definition? If not, what changes would make the definition acceptable?
- b. Who is/should be eligible for short-term acute home care, and how is/should eligibility be determined?
- c. Does your jurisdiction currently publicly fund short-term acute home care?
- d. Which of the services listed below are currently publicly funded for short-term acute home care? Please describe any limits on the amount of each type of service, and any co-pays or user charges for each service.
  - Nursing
  - Other professional service (list)
  - Pharmaceuticals
  - Medical equipment/supplies
  - Essential personal care
  - Client assessment
  - Case management
- e. Are there waiting lists for any of the above services? If so, please indicate for which services, and the average waiting time for your jurisdiction? Are there variations across regions? Please describe the nature and cause of the variation.
- f. Can you please describe “best practice” programs/services for short-term acute care in your jurisdiction? For the purposes of obtaining more detailed information, can you also please provide contact information for the program/service?

### **3. Acute Community Mental Health**

- a. How does your jurisdiction define acute community mental health?
- b. Who is/should be eligible for acute community mental health, and how is/should eligibility be determined?
- c. Does your jurisdiction currently publicly fund acute community mental health services?
- d. Which of the services listed below are currently publicly funded for acute community mental health? Please describe any limits on the amount of each type of service, and any co-pays or user charges for each service.
  - Nursing
  - Other professional service (list)
  - Pharmaceuticals
  - Medical equipment/supplies
  - Essential personal care
  - Client assessment
  - Case management

e. Are acute community mental health services currently delivered through your home care program or through other programs? Please describe. In the future, do you plan to deliver them through your home care program? Please explain.

f. Are there waiting lists for any of the above services? If so, please indicate for which services, and the average waiting time for your jurisdiction? Are there variations across regions? Please describe the nature and cause of the variation.

g. Can you please describe “best practice” programs/services for acute community mental health care in your jurisdiction? For the purposes of obtaining more detailed information, can you also please provide contact information for the program/service?

#### **4. End-Of-Life Care**

CIHI defines an end-of-life client as a “client with a health condition that is not responsive to curative treatment. The client and/or family has been informed by a physician that the client is expected to live less than six months.”

a. How does your jurisdiction define end-of-life care? Does your jurisdiction agree with the above definition? If not, what changes would make the definition acceptable? Does your jurisdiction distinguish between palliative care and end-of-life care? Please describe.

b. Who is/should be eligible for end-of-life care, and how is/should eligibility be determined?

c. Does your jurisdiction currently publicly fund end-of-life care?

d. Which of the services listed below are currently publicly funded for end-of-life care? Please describe any limits on the amount of each type of service, and any co-pays or user charges for each service.

- Nursing
- Other professional service (list)
- Pharmaceuticals
- Medical equipment/supplies
- Essential personal care
- Client assessment
- Case management

e. Are there waiting lists for any of the above services? If so, please indicate for which services, and the average waiting time for your jurisdiction? Are there variations across regions? Please describe the nature and cause of the variation.

f. Can you please describe “best practice” programs/services for end-of-life care in your jurisdiction? For the purposes of obtaining more detailed information, can you also please provide contact information for the program/service?

#### **5. Measurement and Reporting of Each Accord Item**

a. Does your jurisdiction use a common assessment tool for home care? If yes, what is it? Does it have a common assessment tool for any of the above Accord areas? If yes, what are they? Are these elements of the tool compatible with RAI-HC elements?

b. Does your jurisdiction use a paper or electronic assessment platform? If information is currently collected on paper, is it transposed into electronic records?

c. Can your jurisdiction separate out and report on **short-term acute care** cases as defined by CIHI from other types of home care cases? As defined by your jurisdiction, if it is different from the CIHI definition?

- i. Please describe what information can currently be reported?
- ii. Please provide, if possible, annual data from the most recent year available on:
  - total expenditures on short-term acute home care;
  - per capita spending on short-term acute home care;
  - short-term acute home care expenditure as a proportion of total home care spending.
  - Average waiting times for this service
- iii. If your jurisdiction is not in a position to report on short-term acute home care yet, when will it be able to? What are the barriers to reporting on them now? What is needed to be able to report on them?

d. Can your jurisdiction separate out and report on **acute community mental health** cases from other types of home care cases?

- i. Please describe what information can currently be reported?
- ii. Please provide, if possible, annual data from the most recent year available on:
  - total expenditure on acute mental health home care;
  - per capita spending on acute mental health home care;
  - acute mental health home care expenditure as a proportion of total home care spending.
  - Average waiting times for this service
- iii. If your jurisdiction is not in a position to report on acute mental health home care yet, when will it be able to? What are the barriers to reporting on them now? What is needed to be able to report on them?

e. Can your jurisdiction separate out and report on **end-of-life care** cases as defined by CIHI from other types of home care cases? As defined by your jurisdiction, if a different definition is used?

- i. Please describe what information can currently be reported?
- ii. Please provide, if possible, annual data from the most recent year available on:
  - total expenditure on end-of-life care;
  - per capita spending on end-of-life care;
  - end-of-life care as a proportion of total home care spending.



- Average waiting times for this service
  - iii. If your jurisdiction is not in a position to report on end-of-life care yet, when will it be able to? What are the barriers to reporting on them now? What is needed to be able to report on them?
- f. Can you currently report on the **2003 Accord Annex A on Performance Indicators** (see Appendix 1) in general and for short-term acute home care, community mental health, and end-of-life services?
- i. Please describe what can be reported?
  - ii. If your jurisdiction is not in a position to report yet on the Accord performance indicators, when will it be able to? What are the barriers to reporting on them now? What is needed to be able to report on them?

### **III. BEST PRACTICES**

1. Other than best practices described earlier, are there any other home care programs/services in your jurisdiction considered to be “best practice”? Please describe. For the purposes of obtaining more detailed information, can you also please provide contact information for the program/service?

### **IV. OPPORTUNITIES, CHALLENGES AND EMERGING ISSUES**

1. Overall, what are considered to be the major opportunities to providing or improving home care services in your jurisdiction?
2. Overall, what are considered to be the major challenges and barriers that need to be overcome in providing or improving home care services in your jurisdiction?
3. What are some of the emerging issues in home care for your jurisdiction?

## Annex A to Accord

### Performance Indicators

First Ministers direct Health Ministers to develop further indicators to supplement the work undertaken in follow-up to the September 2000 Communiqué (FMM 2000). This work is to be completed by September 2003, following review by experts and stakeholders, to ensure these new indicators measure progress on achieving the reforms set out in this Accord and meet the following objectives:

- Timely Access: the measurement of access to essential services across the country as well as waiting times;
- Quality: the measurement of quality of health care services across the country, including patient safety, patient satisfaction and health outcomes;
- Sustainability: including measurements of the state of health human resources, equipment, information systems and value for money from the system; and
- Health Status and Wellness.

Ministers are to consider the following:

#### Timely Access Indicators

##### *Access to health care providers/services*

- percentage of population having a regular family doctor (FMM 2000)
- percentage of doctors accepting new patients
- number of multidisciplinary primary health care organizations or teams by region (rural/urban)
- percentage of population having access to 24/7 primary care provider (e.g., nurse practitioner, doctor)/telehealth/online health information
- percentage of population routinely receiving needed care from a multidisciplinary primary health care organization or team
- percentage of population with public coverage of core set of home care services

##### *Wait times/volume measures for*

- radiation therapy for breast and prostate cancer, cardiac bypass surgery, hip and knee replacement surgery (FMM 2000)
- referral to specialists for cancers (lung, prostate, breast, colo-rectal), heart and stroke
- emergency rooms from entry to discharge (seasonally adjusted)
- diagnostic tests (MRI, CT)
- from referral to provision of first home care service
- waiting period before being eligible for public coverage of home care services in another jurisdiction
- proportion of services/facilities linked to a centralized (provincial/regional) wait list management system for selected cancers and surgeries, referral to specialists, emergency rooms and diagnostic tests (all of the above wait time indicators)

### *Catastrophic drug coverage*

- to be developed

## **Quality Indicators**

### *Patient safety*

- reported medical error/events (e.g., disease surveillance, adverse drug reactions) - to be determined by proposed Institute on Patient Safety

### *Patient satisfaction (FMM 2000)*

- overall health care services
- hospital care
- physician care
- community-based health care
- telehealth/online information

### *Health outcomes*

- readmissions for selected conditions
  - AMI, pneumonia (FMM 2000)
  - congestive heart failure, GI haemorrhage
- mortality rate for cancers (FMM 2000)
- survival rate for cancers (FMM 2000)

## **Sustainability (Efficiency and Effectiveness) Indicators**

### *Health human resources*

- age distribution of practicing providers by area of specialty
- number of providers (by specialty) leaving/entering the system each year
- a 10-year rolling forecast of providers expected to enter system (trained in Canada, incoming from other countries)

### *Equipment*

- number and types of equipment installed
- number of diagnostic professionals to operate equipment
- volume flow/wait times for MRI, CT (covered under access indicators)

### *Information systems*

- progress on building information systems
- degree of standardization of information collected and shared for evidence-based decision-making
- degree of technology utilization based on evidence

*Value for money - qualitative indicators primarily*

- annual health reports on plans and priorities reported by every jurisdiction
- expenditures linked to reform areas (link inputs to outputs)
- lessons learned and best practices shared within and between provinces/territories
- comparisons of productivity measures

### **Health Status and Wellness**

- percentage of Canadians engaged in physical activities
- percentage of Canadians with recommended Body Mass Index (BMI)
- potential years of life lost (PYLL)
- disability-Free Life Expectancy (DFLE)
- cost of Illness

- 
1. *Nothing in this document shall be construed to derogate from the respective governments' jurisdictions. This Accord shall be interpreted in full respect of each government's jurisdiction.*

**Appendix 2:**  
**Questionnaire to Key Experts**

## **Health Council of Canada Working Group on Home Care**

The Working Group on Home Care is interested in the opinion and advice of key experts on the subject of home care. In particular, the Working Group is seeking input on the elements of home care services identified in the 2003 Accord; namely, short-term acute home care, acute community mental health, end-of-life care, and a common basket of services for these service areas.

Should you require any clarification of the questionnaire, please feel free to contact me by phone at (416) 921-5973 or by email at [pat.baranek@utoronto.ca](mailto:pat.baranek@utoronto.ca). Should you have any questions about the Health Council, please feel free to contact Cathy Fooks, Executive Director by phone at (416) 481-7397 ext. 2398 or by email at [cfooks@hcc-ccs.ca](mailto:cfooks@hcc-ccs.ca).

### **1. Short-term Acute Home Care**

CIHI defines an acute home care client as a “client with acute health or post surgical condition(s) with clearly identified and predictable outcomes or expected recovery.”

- a. How would you define short-term acute home care? Do you agree with the above definition? If not, how would you change it and why?
- b. Who should be eligible for short-term acute home care, and how should eligibility be determined?
- c. What services should be fully publicly funded for short-term acute home care?
  - Nursing
  - Other professional (please list)
  - Pharmaceuticals
  - Medical equipment/supplies
  - Personal care/support
  - Client assessment
  - Case management
  - Home making
  - Support services – please list if applicable
  - Others
- c. The provincial/territorial governments in defining a basket of services for short-term acute home care put a maximum limit on services of two weeks. Could you please comment on the appropriateness of this decision?
- d. From your understanding of the research literature and various innovative practices in the field, what would you consider to be the key elements of best practice in short-term acute home care? Can you please give real life examples?
- e. What performance indicators would you suggest in monitoring the progress of federal/provincial/territorial governments in implementing short-term acute care?
- f. What do you see as the three or four major barriers in jurisdiction’s implementation of short-term acute care services?

## 2. Acute Community Mental Health

- a. How would you define acute community mental health?
- b. Who should be eligible for acute community mental health services, and how should eligibility be determined?
- c. What services should be fully publicly funded for acute community mental health?
  - Nursing
  - Other professional (please list)
  - Pharmaceuticals
  - Medical equipment/supplies
  - Personal care/support
  - Client assessment
  - Case management
  - Home making
  - Support services – please list if applicable
  - Others
- c. The provincial/territorial governments in defining a basket of services for acute community mental health put a maximum limit on services of two weeks. Could you please comment on the appropriateness of this decision?
- d. Acute community mental health services in most jurisdictions are often not delivered through the home care program, and if they are, eligibility frequently requires that the client have a physical as well as a mental condition. Could you please comment on whether it is more appropriate for acute community mental health services to be delivered through home care programs or through the community mental health sector? Please provide an explanation for your view?
- e. From your understanding of the research literature and various innovative practices in the field, what would you consider to be the key elements of best practice in acute community mental health? Can you please give real life examples?
- f. What performance indicators would you suggest in monitoring the progress of federal/provincial/territorial governments in implementing acute community mental health care?
- g. What do you see as the three or four major barriers in jurisdiction's implementation of acute community mental health care?

## 3. End-of-life Care

CIHI defines an end-of-life client as a “client with a health condition that is not responsive to curative treatment. The client and/or family has been informed by a physician that the client is expected to live less than six months.”

- a. How would you define end-of-life care? Do you agree with the above definition? If not, how would you change it and why?

- b. Do you think palliative care is different from end-of-life care? If so, could you please explain the difference?
- c. Who should be eligible for end-of-life care, and how should eligibility be determined?
- d. What services should be fully publicly funded for end-of-life care?
- Nursing
  - Other professional (please list)
  - Pharmaceuticals
  - Medical equipment/supplies
  - Personal care/support
  - Client assessment
  - Case management
  - Home making
  - Support services – please list if applicable
  - Others
- e. The provincial/territorial governments in defining a basket of services for end-of-life care did not put a maximum limit on services of two weeks. Could you please comment on the appropriateness of this decision?
- f. From your understanding of the research literature and various innovative practices in the field, what would you consider to be the key elements of best practice in end-of-life care? Can you please give real life examples?
- g. What performance indicators would you suggest in monitoring the progress of federal/provincial/territorial governments in implementing end-of-life care?
- h. What do you see as the three or four major barriers in jurisdiction's implementation of end-of-life care?

#### **4. Opportunities, Challenges and Emerging Issues**

- a. *Overall*, what would you consider to be the major opportunities in improving home care services in Canada?
- b. *Overall*, what do you consider to be the major challenges in improving home care services in Canada?
- c. What do you consider to be the major emerging issues for home care in the near future?



## **Appendix 3**

### **Jurisdictional Definitions of Short-Term Acute Home Care**

## **FEDERAL JURISDICTIONS**

**Health Canada:** Health Canada supports a definition that includes both clients with acute health conditions and those with post surgical conditions.

**Veterans Affairs Canada:** Not applicable

**Indian and Northern Affairs Canada:** The definition by the First Nations and Indian Home and Continuing Care program is primarily post hospital care. Short-term acute home care is not defined under INAC's Assisted Living Program.

**RCMP:** Short-term acute home care is the provision of a basket of health and support services to individuals experiencing an acute episode of illness or injury. The goal is to avoid admission to or reduce the length of stay in an acute care facility/hospital.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

**Saskatchewan:** Saskatchewan Health defines acute home care as that provided in "situations (other than palliative care) in which the home care program is providing a service that might otherwise be provided in a hospital. In many cases, the services will be provided to a person recently discharged from hospital. Acute care can also refer to services provided by the home care program that eliminate the need for hospital care."

**Manitoba:** The province does not have an exact definition for short-term acute home care, but its Home Care program has viewed short-term as based on a recovery time within 60 days.

**Nova Scotia:** According to its Policy and Procedure Manual 1997, Nova Scotia defines an acute episodic illness as an illness or condition of short duration and relatively severe course which is a pronounced deviation from the normal state of health of the individual. The province currently does not include post surgical conditions in acute home care. The CIHI definition is problematic in that it does not define "short-term."

**Prince Edward Island:** PEI defines "acute care substitution" as one of five core Home Care and Support program components. It is defined as "time limited health services intended to promote recovery from an acute episode of illness or surgery. The goals are to prevent an acute care *re-admission* [emphasis added] and/or reduce the length of stay in an acute care facility."

**Newfoundland and Labrador:** The province does not have a definition of short-term acute home care but finds the CIHI definition acceptable as long as service provision be limited to a maximum of two weeks.

**Yukon:** The territory has adopted the CIHI definition, which also includes "services intended to promote recovery from an acute illness or surgery. Services are time-limited and may vary from low to high intensity."

**Northwest Territories:** The NWT does not have a definition for STAHC but uses "acute home care" as the services provided to clients assessed, admitted for service and discharged within three months. The CIHI definition is acceptable to the Territories.

## **Appendix 4**

### **Current Federal/Provincial/Territorial Short-Term Acute Home Care Services/Programs**

## **FEDERAL JURISDICTIONS**

### **Veterans Affairs Canada (VAC):**

Veterans Affairs Canada has a national home care program, Veterans Independence Program (VIP), which assist clients to remain healthy and independent in their own home or communities. VIP is not intended to replace other federal, provincial or municipal programs but rather supplement or complements them to meet needs. VAC provides nursing and other professional services (unspecified), drugs, medical equipment/supplies, essential personal care, client assessment and case management. VAC provides all these services to eligible clients, however, not within the context of a short-term acute home care programs.

### **Indian and Northern Affairs Canada:**

Each community assesses its ability and capacity to deliver to short-term acute home care services and eligibility depends on the community's capacity to provide care in a safe manner by trained providers. The First Nations and Inuit Home and Continuing Care program does provide post-hospital discharge care based on an assessment. Services include nursing, which is publicly funded but is dependent on the availability of a nurse who has had additional training and access to clinical expertise; drugs, which are funded through the Non-Insured Health Benefits Program; essential personal care, which is dependent on availability; publicly funded client assessment; and case management (more resources are required).

### **RCMP:**

There is no standard organization for a national home care provider. Each RCMP health unit arranges for the provision of home care through a memorandum of understanding between a home care provider agency (e.g., VON) and the RCMP Medical Clinic. The MOU is available only to RCMP Members living in the catchment area. An RCMP Regular Member is a member employed in the capacity of a police officer with an active regimental number. Retired members, civilian members and those who have resigned from the force are not eligible for the program. Services include nursing services, case management and assessment, and referral to other specialty programs, such as, IV therapy, wound and continence care, food care and diabetes. Upon approval, the home care provider can refer a client to another provider for services.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

### **British Columbia:**

One of the mandates of the BC Home and Community Care services is to “provide services at home to clients who would otherwise require admission to hospital or would stay longer in hospital.”<sup>74</sup> Professional services, which include nursing, rehabilitation, social work, health services in school, assessment and case coordination are provided without charge to acute home care clients. Medical supplies are provided for two weeks and clients, on rehabilitation program, are assessed for equipment/aids but are responsible for the rental. Home support services (assistance with daily living) may be provided depending on need.

### **Saskatchewan:**

The province provides home care services to clients based on assessed need and risk. Nursing, rehabilitation (PT, OT, limited SPL), medical equipment/supplies (home IV drugs and supplies, some nursing supplies), client assessment and case management are fully funded. Drugs (through

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<sup>74</sup> Canadian Home Care Association, 2003. *Portraits of Home Care: A Picture of Progress and Innovation*. p.16.

the Saskatchewan Drug Plan), personal care, respite, meals, home management and maintenance involve a user fee or co-payment. Saskatchewan has developed a policy on home IV therapy.

**Manitoba:**

Manitoba's home care mandate includes the prevention of premature admission to or over-stay in a care facility.<sup>75</sup> Manitoba provide nursing, OT and PT assessment, drugs (partial coverage), medical equipment and supplies from an approved list, essential personal care, client assessment and case management to clients who have been assessed in hospital as requiring acute home care.

**Nova Scotia:**

Acute home care in this province provides nursing services, and may provide personal care and/or home support services to meet the needs of individuals with acute episodic illnesses that may be treated safely and effectively within the home. Acute home care services are generally provided for a period of up to 15 days. Where circumstances warrant, extended admissions to acute home care may be authorized. The client's physician determines the medical suitability and stability for acute home care and recommends admission by notifying Home Care Nova Scotia. Clients must be in need of services during an acute illness or condition that would normally require hospitalization for one or more types of intervention from an established list. The ability to provide the care safely and effectively in the home is a priority. The client must be able to receive the care within a safe distance to back up to a physician, hospital or care providing office. Clients must have a diagnosis/prognosis that suggests the condition will resolve within 15 days (with some exceptions). The client must have an identified attending physician who is aware of and has agreed to follow the client in the community. When the referring physician (e.g. from a hospital) will not be caring for the patient in the community, he/she or his/her designate discusses the medical treatment plan with the patient's community physician and ensures the community physician's willingness to be the attending physician while the patient is receiving acute home care. The patient must be medically stable for care in the home and require nursing services alone, or in conjunction with home support services for the duration of admission to the program.

Publicly funded services without fees include care coordination, home support (homemaker services), personal care, nursing services, access to physician services through MSI, and referral to other services. Medical supplies on the Approved Supply List are provided to patients free of charge for the treatment of the acute illness or condition. Home care clients are responsible for borrowing, renting or purchasing medical equipment required in the home. Drugs for the treatment of the acute condition for which the patient is admitted into acute home care is free as long as the patient is in the acute care program; i.e., the Home Care program does not provide medications for pre-existing or chronic conditions not directly related to the acute episode. Generally, patients in the acute home care category are entitled to a maximum combined cost for services and medical supplies (excluding medications) of \$4000 per month, or \$2000 for the first 15 days based on assessed need. Authorization may be given to extend services when an individual's needs exceed the guidelines.

**New Brunswick:**

The New Brunswick Extra-Mural Program (EMP) began accepting its first clients in 1981 and gradually expanded to cover the whole province by 1993. Part of its mandate is to provide an alternative to hospital admissions, facilitate early discharge from hospitals, and provide rehabilitation services. It was seen as a cost saving strategy resulting partly from the economies of not expanding hospital beds. Established within Regional Health Authorities, the EMP provides a basket of services which include acute care, palliative care, long-term care, rehabilitation and

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<sup>75</sup> CHCA, 2003. *ibid.*

oxygen therapy. A physician's referral is required for admission to the program with the exception of rehabilitation services. Professional services include physicians, nursing, OT, PT, SPL, respiratory therapy, social work and clinical nutrition. Nursing services are provided on a 24/7 basis. EMP arranges limited short-term home support services (e.g. personal care) which are funded through the Department of Family and Community Services. Clients who are accepted for home health care services receive necessary drugs and supplies based on need. However, the EMP is payer of last resort for all drugs.<sup>76</sup>

**Prince Edward Island:**

The province uses general home care eligibility criteria who are recovering from an acute episode of illness or surgery. Services provided include client assessment and case coordination, nursing (maximum of three visits or four hours/day), rehabilitation (OT, PT, SPL), dietitian, pharmacist (one region), adult protection, and community support. Essential personal care is provided on a sliding fee scale. Medical equipment and supplies are not publicly funded. There is no separate home care drug program.

**Newfoundland and Labrador:**

Home care is currently available in Newfoundland/Labrador to clients who are discharged from hospital. The ability to provide service depends on the amount and type of intervention required. Nursing services for acute care are provided at various levels throughout the province. Home support for short-term acute care clients is provided from home support funding allocated for seniors and clients with disabilities. The province funds the following services within limits: nursing, social work, PT, OT, dietitian, client assessment and case management. Medical supplies and equipment are provided to a limited degree with the latter requiring a financial means test. Co-payments are required for essential personal care. Drugs are not funded. Clients are admitted to the provincial home support program according to emergency criteria, which include patients discharged from hospital, clients in crisis situations and clients with caregiver breakdown. New clients generally have to wait two to three weeks for rehabilitation services. Referral for nursing services is usually completed with a 24-hour time frame post hospital discharge.

**Yukon:**

Acute care clients who require less than 12 weeks of service are eligible for home care services. Fully publicly funded services include case management, client assessment, nursing, rehabilitation (OT, PT, SPL). Equipment based on availability can be borrowed by clients over 65. The program helps patients under 65 organize rentals. Drugs are only covered for those over 65, on social assistance, and for chronic conditions.

**Northwest Territories:**

In the Northwest Territories anyone with a need identified through an assessment is eligible for acute home care. Nursing, rehabilitation therapies, social work, nutrition, pharmaceuticals, medical equipment/ supplies, essential personal care, client assessment and case management are publicly funded without service limits or user fees. However, availability of financial and human resources limits access to professional services other than nursing and medical equipment. A higher level of service can be found in larger centres, largely due to staff shortages and turnover in the smaller ones.

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<sup>76</sup> New Brunswick Health and Wellness. 2003. The New Brunswick Extra-Mural Program. [www.gnb.ca/0051/0384/pdf/1985e.pdf](http://www.gnb.ca/0051/0384/pdf/1985e.pdf).

**Appendix 5**

**Best Practices in  
Short-Term Acute Home Care**

**Quick Response Programs** (QRPs) provide access for individuals to alternate care in the home and community care. This model involves an interdisciplinary and multi-sectoral approach to problem-solving, decision-making, and delivery of community-based care from a variety of sources. QRPs arrange for additional care in the home as an alternative for individuals who would normally be admitted to the hospital upon presentation at the Emergency Departments. Quick Response Teams divert such people from hospitals to suitable community-based care. Typically, teams assess patients rapidly - usually within two hours - and then refer them to other services. The National Evaluation of the Cost-Effectiveness of Home Care assessed the QRP in Saskatoon in terms of its cost-effectiveness in decreasing hospital admissions. The study found that the QRP is successful in identifying non-acute cases, in diverting them to appropriate home and community care, and is a cost-effective alternative to hospital care. The project indicated that reduction in overall health expenditures will only occur with the closure of hospital beds.<sup>77</sup>

There are a number of Quick Response Programs in BC, Ontario and Alberta. The Quick Response Team launched by the Victoria Health Project won the 2002 John F. McCreary Prize in recognition of inter-professional teamwork in the health professions. The team provides crisis intervention to people in their homes, with services available from 8 a.m. to 11 p.m., 365 days a year. A description of the program is provided elsewhere.<sup>78</sup> Participants are from a variety of disciplines including nursing, physiotherapy, social work, medicine and pharmacy.

The elderly are one of the heaviest users of emergency departments and hospital services. To address this, the *Comprehensive Home Option of Integrated Care for the Elderly (CHOICE)*, (based on Programs of All-Inclusive Care for the Elderly (PACE) in the US) was developed in January 1996 in Edmonton in partnership with the Good Samaritan Society and the Capital Health Group. The umbrella program is designed to assist seniors to continue living independently and in their own home longer, by managing all their health requirements. All enrollees come to one of the Capital Care CHOICE day centres from one to five days a week where a full range of medical, psychological, social and supportive services are available from an interdisciplinary team. Hours of operation are 8:00 a.m. to 4:15 p.m. with emergency response available 24/7. Intravenous care can be provided for a few days in a CHOICE facility. Services include:

- medical monitoring and treatment by CHOICE physicians, psychiatrists and nurses;
- foot care, dental and eye care screening;
- physical, occupational and recreation therapy;
- personal care (help with dressing, bathing, nail, foot and hair care);
- assistance with meals and snacks;
- assistance with nutrition;
- assistance with meals and personal care provided at home as needed;
- loan of equipment such as walkers and railings if required;
- transportation to and from the CHOICE Programs;
- overnight stays during treatment for short-term illness.<sup>79</sup>

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<sup>77</sup> Franko J. 2001. *Substudy 14: Evaluation of the Cost-Effectiveness of the Quick Response Program of Saskatoon District Health*. A report prepared for the Health Transition Fund, Health Canada. [www.homecarestudy.com/reports/full-text/substudy-14-final\\_report.pdf](http://www.homecarestudy.com/reports/full-text/substudy-14-final_report.pdf)

<sup>78</sup> Rachlis M. 2004. *Prescription for Excellence. How Innovation is Saving Canada's Health Care System*. Toronto: Harper Collins Publishers Ltd.

<sup>79</sup> The Capital Care Group. [www.capitalcare.net/Programs/CHOICE/choice.htm](http://www.capitalcare.net/Programs/CHOICE/choice.htm)



Preliminary evaluations demonstrate that patients are much less likely to end up in hospital after they join the program.<sup>80</sup>

***Integrating Physicians Services in the Home*** (IPSITH) is a project in London, Ontario which provides a multidisciplinary model of care for treating acute and complex illnesses in the home. Along with the family physician, a nurse practitioner, specialists, community nurses, the team is supported by laboratories, pharmacies, oxygen suppliers and diagnostic services. An evaluation of the project funded by the CHSRF found that although the program cost more than the usual home care (an average of \$1270 more per patient), it provided more benefit and cost much less than hospitalization for the same diagnosis (\$400 to \$1900 less per episode). Non-IPSITH patients used emergency room services at approximately three times the rate of the sicker IPSITH patients. IPSITH patients, their caregivers, family physicians, and nurses reported significantly higher satisfaction with care than the non-IPSITH group. The 24/7 availability of a nurse practitioner turned out to be key in the success of the project by addressing the lack of availability of highly skilled community nurses and IV nursing teams, and also to address some of the barriers to participation cited by physicians (travel time, sacrifice of office/personal time, and poor remuneration). The evaluators indicate that this may be an alternative to hospital care in some cases. However, they caution that time, fair remuneration for family physicians, and commitment on the part of government and programs are required to ensure the integration of services.<sup>81</sup>

***Home intravenous antibiotics and wound care*** are proving to be cost-effective alternatives to hospitalization. CIHI reported over 23,000 hospital admissions for skin infections and wounds in 2000, a number of which could have been treated at home through these programs. There are examples of projects and studies across Canada cited in the literature.<sup>82</sup>

New Brunswick's ***Extra-Mural Program*** has been considered a best practice in Canada by many. The Extra Mural Hospital (EMH) was founded in 1981 as was the first home-hospital program, designated as a hospital corporation under the New Brunswick Hospital Act. Its mandate was to provide hospital services at home to a level compatible with tertiary home care along with long-term continuous health care and rehabilitation to those requiring chronic care, palliative care, and to be persons with disabilities. In 1996 the EMH became the Extra Mural Program and its management devolved to the eight regional hospital corporations which manage hospital facilities, community health care centres and the EMO. All staff are employees of the EMP and work in cross disciplinary teams. Support services are contracted. Acute care under the EMP is to facilitate early discharge or to prevent admissions to hospitals or more costly facilities; to improve or restore function through interventions in the client's natural environment. Services include chemotherapy, oxygen therapy, diabetes management, IV therapy, wound care, intravenous hydration and medication administration, and post-operative rehabilitation.<sup>83</sup>

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<sup>80</sup> Christie B et al. 2004. What's new for the old. *Canadian Healthcare Manager*. October/November:23-29, as cited in Rachlis M. 2004. *ibid*.

<sup>81</sup> Stewart M et al. 2002. Evaluation of an Organization for Integrating Physician Services in the Home. [www.chsrf.ca/final\\_research/ogc/pdf/stewart\\_e.pdf](http://www.chsrf.ca/final_research/ogc/pdf/stewart_e.pdf).

<sup>82</sup> Rachlis M. 2004. *ibid*

<sup>83</sup> New Brunswick Health and Wellness. 2003. The New Brunswick Extra-Mural Program. [www.gnb.ca/0051/0384/pdf/1985e.pdf](http://www.gnb.ca/0051/0384/pdf/1985e.pdf).

River Valley Health, one of New Brunswick's Authorities, has planned an expansion of its Extra Mural Program (EMP) to include access to telehomecare. The River Valley Health EMPcare@home will be piloted in 2004-2005.<sup>84</sup>

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<sup>84</sup> New Brunswick Health and Wellness. River Valley Health Develops Telehomecare Ability (news release, March 18, 2004).  
[www.atl.bluecross.ca/wabccnew.nsf/0/19ec7e73f7e1248f84256e7b0068f77b?OpenDocument](http://www.atl.bluecross.ca/wabccnew.nsf/0/19ec7e73f7e1248f84256e7b0068f77b?OpenDocument)

**Appendix 6**

**Jurisdictional Definitions of  
Acute Community Mental Health**

## **FEDERAL JURISDICTIONS**

**Veterans Affairs Canada:** VAC has not defined acute community mental health, per se. However, within VAC's Mental Health Framework, VAC identifies specific problems affecting elderly clients and Canadian Forces (CF) members. VAC's wartime veteran clients are in the very elderly category in the life continuum and are therefore more likely to experience particular mental and physical health problems unique to the process of aging. Behavioural disturbances such as verbal and physical aggression, agitation and insomnia, associated with mental disorders, results in patient and caregiver distress, compromising the quality of life of patients and their families. This is often the reason families decide on institutionalization. Canadian Forces (CF) members are particularly concerned about mental disorders because members are not only exposed to the problems of a "normal" life, but also to those of a high risk career. Military life places additional stresses on its members that may contribute to the incidence of mental disorders; these stresses include sudden and prolonged isolation from families and established support systems; exposure to dangerous environments; anxiety and stress related to high performance expectations; restriction of choice and freedom; imposed discipline; and numerous moves.

**Indian and Northern Affairs Canada:** Preliminary investigation of services provided by the FNIHCC program shows that most mental health needs seen by home care workers are chronic – typically depression, post-traumatic stress disorder, suicidal tendencies and to a lesser extent, the long-term patterns of disease from schizophrenia and bipolar disorder. The INAC Assisted Living jurisdiction has no definition for acute community mental health.

**RCMP:** Short-term acute community mental health care is the provision of a basket of health and support services to individuals experiencing an acute mental disorder/illness. The goal is to avoid admission to or reduce the length of stay in an acute facility/hospital.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

**Saskatchewan:** Saskatchewan Health does not currently have a definition for acute community mental health but supports the definition forwarded by the F/P/T Home Care Basket of Services Working Group.

**Manitoba:** The province does not have a formal definition have acute community mental health.

**Ontario:** The Ontario government in its recent mental health reform initiatives defined a mental health crisis as "the onset of an emotional disturbance or situational distress (which may be cumulative), involving a sudden breakdown of an individual's ability to cope. Crisis intervention refers to active treatment and support offered as soon as possible after an individual has been identified as in acute distress. There is a need to provide immediate relief from symptoms and rapid stabilization so that the condition does not worsen. ... It holds the potential of mobilizing community resources and averting the need for short and/or long-term hospitalization."<sup>85</sup>

**Nova Scotia:** Acute community mental health services are not provided under Nova Scotia's home care program.

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<sup>85</sup> Ontario Ministry of Health. 1999. *Making It Happen: Operational Framework for the Delivery of Mental Health Services and Reports*. Toronto: Queen's Printer for Ontario.

**Prince Edward Island:** PEI agrees with the FPT Working Group’s recommendations that acute community mental health services should focus on individuals experiencing an acute mental health disorder/illness (i.e., an acute illness and/or an acute episode of a chronic illness).

**Newfoundland and Labrador:** The province currently does not have a definition of acute community mental health, but it does agree with the definition reached by the FPT Working Group.

**Yukon:** The territory does not use the term acute community mental health. Rather it refers to persons with diagnosable mental health problems (using DSM-IV criteria). Within this broad group, it distinguishes persons with serious and persistent mental illnesses (SPMI).

**Northwest Territories:** There is currently no definition specific to acute community mental health. In the context of Mental Health and Addiction Services acute community mental health would be defined as those services delivered to clients presenting with a mental illness (e.g. anxiety disorder, depression) and experiencing a “crisis” determined either organically/ biochemical (e.g. mania, psychosis) or through a perceived psycho-social crisis (e.g. loss of a significant other).

## **Appendix 7**

### **Current Federal, Provincial, and Territorial Programs for Acute Community Mental Health**

## **FEDERAL JURISDICTIONS**

### **Veterans Affairs Canada:**

VAC does not fund acute community mental health services as part of a home care program. However, eligible clients may be able to access some specific professional services. Nursing, other professional services, drugs, medical equipment/supplies, essential personal care, client assessment and case management are services included in the suite of programming and services offered by VAC under the Veterans' Independence Program and treatment benefits.

### **Indian and Northern Affairs Canada:**

The First Nations and Inuit mental health system is undergoing an evolution from a fragmented collection of services in a variety of programs, jurisdictions and disciplines to a coherent, linked network of service providers. In addition to front line community health nurses and community health representatives, some funding is available from two community wellness programs for mental health services (Brighter Futures and Building Healthy Communities). Other service providers include drug and alcohol addictions workers. The Non-Insured Health Benefits program of the First Nations and Inuit Health Branch provides access to medical transportation to enable clients to access acute community mental health services from a province. Some short-term medical intervention can also be obtained from the Non-Insured Health Benefits Program. Provincial and territorial health services offer insured mental health services to First Nations and Inuit, generally off reserve. Under the First Nations and Inuit Home and Community Care Program (FNIHCC), the limits placed on the availability of these services are primarily based on availability of resources. Preliminary survey of mental health home care services under the FNIHCC program would indicate that there is a need, but the service focus has been services to those living with chronic disease and disabilities.

### **RCMP:**

Although the RCMP responded to the survey, it did not provide information specific to acute community mental health services.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

### **Saskatchewan:**

No specific short-term acute community mental health program is currently in place in Saskatchewan. However some services that may be considered part of acute community mental health are offered. All Saskatchewan residents with a valid health registration are eligible for these services, based on assessed need by a qualified health professional. All are publicly funded, but a co-payment may apply for certain services. Currently Saskatchewan Health provides funding to the Regional Health Authorities to provide mental health services.

There is limited access to services for clients with both Home Care and Mental Health services needs. These include:

- nursing
- assessment & case management
- crisis services
- psycho-social counseling
- PT/OT/SLP – limited
- dietetics - limited
- pharmaceuticals – user fee, for medications the physician may put application in to Saskatchewan Health for Exceptional Drug Status (EDS)
- medical equipment and supplies – user fee.

- personal care – limited, user fee

Community mental health services are delivered through the mental health programs in each Regional Health Authority. Each mental health program has a specific Psychiatric Rehabilitation Program to support persons with severe long-term problems.

If a short-term acute community mental health program were implemented in Saskatchewan, no final decision has been made with respect to how it would be delivered. It is expected, however, that it would be delivered through mental health programs in the Regional Health Authorities rather than through the traditional home care programs.

**Manitoba:**

Through its Regional Health Authorities and agencies, Manitoba does fund acute community mental health services. These services are not delivered through the Home Care Program and there are no plans to change this. Acute community mental health services include occupational therapy, client assessment, general and intensive case management, assertive community treatment, and proctor services. Most regions in Manitoba have Mobile Crisis Units, Crisis Stabilization Units, Safe Homes, Critical Incident Stress Debriefing Teams, and Crisis Lines.<sup>86</sup>

- Mobile Crisis Units provide crisis intervention and suicide prevention services to persons experiencing emotional or mental health crises. Services are provided in the community, usually within residences and include screening and psychiatric assessment, crisis intervention and counselling, referral and short-term follow-up with other mental health and social services.
- Crisis Stabilization Units are short-term community-based settings that provide mental health intervention to persons who require specialized mental health supports but not hospitalization. Crisis stabilization units usually have a nurse on shift who is able to assist with medication management and other medical and psychiatric issues. Individual stays in crisis stabilization units vary considerably, but usually do not exceed two weeks.
- Safe Houses are short-term residential settings for individuals who require a caring, supportive environment to help them manage an emotional or mental health crisis. Safe houses are often staffed by consumers, and usually do not have the nursing expertise to manage acute psychiatric crises.
- Critical Incident Stress Debriefing Teams provide immediate and short-term interventions to persons who have experienced a potentially traumatic event. Critical events can include suicides, murders, major accidents and other emergencies. Critical incident debriefing teams provide post-trauma debriefings, education, and referral to longer-term community resources.
- Crisis Lines provide telephone crisis intervention and suicide prevention services by trained volunteers and staff. These services provide immediate and short-term interventions, and can serve as referral links to other community mental health services. Most mobile crisis units and crisis stabilization units also provide telephone crisis intervention.

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<sup>86</sup> Manitoba Health. Guide to the Mental Health System In Manitoba. [www.gov.mb.ca/health/mh/system.html](http://www.gov.mb.ca/health/mh/system.html). Accessed August 16, 2004.



Individuals experiencing mental health issues are eligible for services based on assessed need, within program limits. Because there is only one Program for Assertive Community Treatment in Winnipeg, there is currently a waiting list for these services.

**Ontario:**

In Ontario mental health services are funded and delivered separately. The government in its 1999 operational framework document outlined the goals and functions of a crisis response intervention services, intensive case management, and assertive community treatment teams which operate within the mental health system.<sup>87</sup> A mobile crisis team provides 24-hour capability to provide rapid assessment and intervention in an array of environments, including clients' homes, shelters and other community environments. In some instances the team is based in a hospital operating near its emergency area. The specific functions of a crisis services could include assessment and planning, crisis support/counseling, medical intervention, environmental interventions and crisis stabilization, review/follow-up/referral, and information, liaison, advocacy, and consultation/collaboration. Examples of crisis programs include telephone crisis services; mobile crisis units, crisis residential services, and psychiatric emergency/medical crisis services in hospitals.

Intensive case management services in Ontario provide outreach and client identification, comprehensive assessment and planning, direct service provision, coordination and support, monitoring and evaluation. Key features of intensive case management services include proactive outreach, caseloads of 15 to 20, one-fifth of clients should be seen more than once a week, 50 per cent of contact should take place outside the office, and 24 hour access to system services.

Assertive Community Treatment Teams (ACTT) are self-contained clinical teams that provide treatment, rehabilitation and support services to identified clients with severe and persistent mental illnesses. Clients of ACTT tend to be homeless, abusing substances, have involvement with the criminal justice system, and make frequent use of emergency systems and/or hospitals, and/or resistant to treatment. Services are provided on a long-term basis emphasizing continuity of caregivers over time. Features of the service includes assertive outreach, round the clock unlimited care provided in the community, flexible support tailored to clients' needs, and client and family involvement. Functions of the ACTT include case management, crisis assessment and intervention, symptom assessment and management, medication prescription/administration/monitoring, substance abuse services, work related services, activities of daily living, social and leisure skill training, support services, education.

On June 14, 2004, the Minister of Health announced an investment of \$583 million over four years for community mental health. The investment will expand case management for people living with mental illnesses, crisis response services for individuals who are in acute distress, as well as early intervention programs.<sup>88</sup>

Within the Ontario home care program, mental health service provision varies by Community Care Access Centres. Those that do provide services to the seriously mentally ill offer some or all of the following: functional assessment, personal support, nursing care (medication monitoring),

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<sup>87</sup> Ontario Ministry of Health. 1999. *Making It Happen: Operational Framework for the Delivery of Mental Health Services and Reports*. Ibid.

<sup>88</sup> Ontario Ministry of Health and Long Term Care. 2004. Mental Health Announcement (Speech by the Minister of Health, The Hon. George Smitherman). [www.ofcmhap.on.ca/ministry/MH%20Announcement%20June%2014.htm](http://www.ofcmhap.on.ca/ministry/MH%20Announcement%20June%2014.htm), Accessed August 17, 2004.

coordination of services, respite, medical equipment and tests. However there are inconsistent interpretations as to how mental health services fit within the CCAC mandate. Coordination of services to mental health clients is difficult because of the limited availability of services and a general lack of resources in the community mental health system (funds and human resources). In addition home care services where available to mental health clients are often terminated before the client reaches a high enough level of functioning. The Ontario Association of Community Care Access Centres is advocating that they be funded to provide specialized mental health support services (case coordination, nursing, occupational therapy, social work and person support services) to adults in the community who have a primary diagnosis of mental illness.<sup>89</sup>

**Nova Scotia:**

Although NS responded to the survey, it did not provide information on acute community mental health services.

**New Brunswick:**

Although NB responded to the survey, it did not provide information on acute community mental health services.

**Prince Edward Island:**

All community mental health services in PEI are provided through the Regional Health Authority Community Mental Health Centres or by partners, i.e. Canadian Mental Health Association and Catholic Family Services Bureau (both of which are partially funded by the Department of Health and Social Services). The province does not have a targeted Acute Community Mental Health program but offers a range of services to Islanders of all ages with a variety of mental health problems from mild to severe and persistent. The following services are publicly funded: nursing, occupational therapy, social work, psychiatry, psychology, crisis services, psycho-social counseling, assertive community treatment teams, early intervention, client assessment and case management. Essential personal care involves a co-pay and medical equipment/supplies are not funded. In general there is a two to four-week wait for CMHC services and a one to two-week wait for psychiatric services. There is no waiting period for crisis intervention services.

**Newfoundland and Labrador:**

Newfoundland does not currently have a mental health home support program. Due to rising expenditures and budget cutbacks, the province is not able to extend home care coverage to prevent or deter hospital admission even for patients with an short-term acute physical condition. Home care services are currently available only for children and youth, seniors and persons with a mental illness who have a concurrent physical or developmental disability. The Health Care Corporation of St. John's runs an Early Psychosis Program for individuals hospitalized with a psychosis for the first time. It is anticipated that such programs will have an indirect effect on public awareness of home support and will inform the development of increased home care/support.

Recognizing that its community mental health services are underdeveloped, Newfoundland has proposed to develop a full continuum of services, including both psychiatric and addictions services.<sup>90</sup> The strategy recommended incorporating community mental health and addictions

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<sup>89</sup> Ontario Association of Community Care Access Centres. 2003 Mental Health Services: Discussion Paper. [www.oaccac.on.ca/paper\\_display.php?id=23](http://www.oaccac.on.ca/paper_display.php?id=23)

<sup>90</sup> Newfoundland/Labrador Department of Health and Community Services. 2003. Working Together for Mental Health: A Proposed Mental Health Strategy for Newfoundland and Labrador.

counselors as a key component of primary health care teams. Also recommended are access to mobile crisis resources for mental health emergencies and the assignment of a mental health case manager to primary health care teams. It is also suggested that mental health/addictions interdisciplinary teams partnered with primary mental health/addictions teams to act as a link with specialized services to ensure communications and follow-up care with the primary health care team should the individual require inpatient care. These interdisciplinary teams may also act as mobile crisis resources and/or case managers.

**Yukon:**

Home-based services to persons with diagnosable mental health problems are delivered by Mental Health Services and are likely to continue to be delivered through this program area. “Home Care” provides in home services to persons with physical health problems. In some cases, there is shared care for a person who has a co-morbidity. For the most part, outreach (i.e. home-based services) is provided to clients with a serious persistent mental illness (SPMI). On occasion, persons diagnosed with serious personality disturbances are also provided home-based care. In all situations, home-based care is provided on an as needed basis, taking into account an individual’s level of functioning and other situation-specific factors. This could include, but is not limited to, follow up upon discharge as well as for the purposes of preventing relapse and/or re-hospitalization.

The Department of Health and Social Services has salaried positions for community mental health nurses and supported independent living workers who provide in-home services as needed. Services include assessment, case management, and nursing services. Drugs are funded out of the Chronic Disease Program. There is currently no waiting list for home care services for persons with diagnosable mental health problems; newly referred individuals are seen as soon as possible but this could impact on level of services provided to other clients.

**Northwest Territories:**

Any individual in the community who is screened and assessed by a mental health counselor, therapist, or psychiatrist as requiring mental health services (i.e. meeting diagnostic criteria for a mental illness or other mental health/addiction) are entitled to services. The Territories publicly fund the following services through their home care program: nursing, other professional services (mental health counselors, addiction counselors, clinical supervisors, and psychiatric nurses), drugs (covered under other benefits programs, essential personal care, client assessment and case management. There are no limits on services or user fees.

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[www.gov.nf.ca/health/publications/pdffiles/Mental%20Health%20Strategy%20Disc%20Doc%20Nov%202003.pdf](http://www.gov.nf.ca/health/publications/pdffiles/Mental%20Health%20Strategy%20Disc%20Doc%20Nov%202003.pdf) . Accessed August 16, 2004.

**Appendix 8**

**Best Practices**

**Acute Community Mental Health**

## **British Columbia**

The Fraser Health Region's Early Psychosis Intervention program was identified recently as a best practice program.<sup>91</sup> It is a collaborative initiative between Fraser Health and Ministry of Children and Family Development, Child and Youth Mental Health, began operating in May 2000 in the south health service area of Fraser Health. The goal of the EPI program is to recognize the signs and symptoms of psychosis early so that effective treatment can be started as soon as possible. Treating psychosis involves education, medication, close monitoring of symptoms, stress management and creating a strong, supportive environment.

The program provides clinical services and education intended to promote wellness, reduce socially isolating behaviour, and restore previous levels of functioning. The EPI program offers clinical services for people: experiencing their first psychotic episode; have a suspected psychosis; have a family history of psychotic disorder; and experiencing a recent deterioration in the ability to function.<sup>92</sup>

## **Alberta**

In Taber, the Mental Health Community Care Pilot Project created a service delivery model that is a three-way partnership with the client/family, the Mental Health Program and the Community Care Program to provide assessment, planning, delivery and evaluation of home-based services. A client receives an initial assessment within the agency of referral. If the client requires the services or involvement of the other agency, a referral is made and the three-way partnership is formed. Through a joint case conference both agencies are involved in developing an interdisciplinary treatment plan. Despite the small numbers of participant in the pilot, the evaluation indicated that the integrated home care and mental health services with a mental health outreach component was an effective way to meet the home care needs of people with mental illness, particularly in rural settings where services are limited and isolation is a critical issue. Through the partnership, the community care nurse does not require the expertise in mental illness.<sup>93</sup>

## **Manitoba**

The Program for Assertive Community Treatment introduced in 2000 is considered to be a best practice in Manitoba. PACT consists of a team of mental health service providers that uses an integrated package of intensive care options to deliver treatment, rehabilitation and support services at the community level. Key benefits of PACT are reported to include increased mental stability and time out of hospital for individuals, reduced hospital costs and enhanced home life stability. The major target population is persons with a primary diagnosis of schizophrenia, schizo-affective disorder or severe affective disorder, and those who have had several psychotic episodes or psychiatric ward hospital stays. A PACT clinical team typically includes a team leader, a psychiatrist and a multidisciplinary group of professionals that may include social workers, nurses, psychologists, occupational therapists, vocational rehabilitation specialists and

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<sup>91</sup> Rachlis M. 2004. *Prescription for Excellence. How Innovation is Saving Canada's Health Care System.* Toronto: Harper Collins Publishers Ltd.

<sup>92</sup> Fraser Health Early Psychosis Intervention. [www.fraserhealth.ca/HealthInfo/MentalHealth/Early+Psychosis+Intervention.htm](http://www.fraserhealth.ca/HealthInfo/MentalHealth/Early+Psychosis+Intervention.htm). Accessed August 17, 2004.

<sup>93</sup> Canadian Mental Health Association. Home Care and People with Psychiatric Disabilities: Taber Pilot Site. [www.cmha.ca/english/hmcare/taber\\_report.htm](http://www.cmha.ca/english/hmcare/taber_report.htm). Accessed August 17, 2004.

substance abuse specialists. Services to individuals are provided at a ratio of 10 clients to one staff. Additional staff may include paraprofessional mental health workers.<sup>94</sup>

### **Ontario**

The Centre for Addictions and Mental Health in Toronto began a First Episode Psychosis Program in 1992. Priority is given to individuals who have not yet received any antipsychotic treatment and are 18 to 45 years old. A referral is required from a family doctor, child or general psychiatrist, or pediatrician. Individuals can be referred either as outpatients to the assessment clinic or to the inpatient unit. Treatment usually involves low-dose antipsychotic drugs and supportive services.<sup>95</sup>

### **Newfoundland:**

For the past two years Newfoundland/Labrador has funded a pilot project in the St. John's Region, which provides case management and home support to a limited number of individuals who have complex mental health needs and who have been involved with the justice system. The outcome for these individuals has been very positive. Need for hospitalization and conflicts with the legal system have been reduced. The funding for the project has been extended and there are plans to expand the program to two other regions in the coming years.

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<sup>94</sup> Manitoba Health. 2000. Health Minister Announces New Community Mental Health Program (news release, May 19, 2000). [www.gov.mb.ca/chc/press/top/2000/05/2000-05-19-01.html](http://www.gov.mb.ca/chc/press/top/2000/05/2000-05-19-01.html). Accessed August 16, 2004.

<sup>95</sup> Centre for Addictions and Mental Health. First Episode Psychosis Clinic/Early Psychosis Unit. [www.camh.net/about\\_camh/Guide\\_SPFirstEpisodePsychosis.html](http://www.camh.net/about_camh/Guide_SPFirstEpisodePsychosis.html). Accessed August 17, 2004.

**Appendix 9**

**Jurisdictional Definitions of  
End-of-Life Care**

## **FEDERAL JURISDICTIONS**

**Veterans Affairs Canada:** Palliative care is care provided to someone who is in the last stages of his/her life. It is distinguished by the purpose for which the tasks are performed rather than by the tasks themselves. The purpose of palliative care is to improve the quality of remaining life rather than to prolong it or affect a cure. It enables the client to die with dignity in a supportive environment surrounded by family and friends. Palliative care is normally provided for a period of up to three months.

**Indian and Northern Affairs Canada:** The First Nations and Inuit Home and Community Care Program does not have a formal definition; however FNIHCC has worked with the National Aboriginal Health Organization (NAHO) to develop a preliminary discussion around palliative care. The working definition used in this document is the WHO definition of palliative care as it is the most compatible with traditional and Aboriginal views. The WHO definition of palliative care is: “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of physical, psychological, social, emotional and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Palliative care also affirms life and regards death as a normal process and neither hastens or postpones death. Palliative care integrates the aspects of care with coordinated assessment and management of each person’s needs and continues after death to support the family in bereavement.”

**RCMP:** Short-term end-of-life care is the provision of a basket of health and support services to individuals dying from a progressive life-threatening illness who may otherwise be hospitalized. The goal is to comfort and support individuals and caregivers through a combination of active and compassionate services and to enable individuals to die at home if they wish to do so.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

**British Columbia:** BC defines end-of-life care as treatment given when an individual has a life-limiting or terminal disease, and he or she has decided not to have any more treatment to cure the disease or prolong life. The goal of end-of-life care is to enhance the quality of the life remaining.<sup>96</sup>

**Alberta:** Palliative refers to patients who have been diagnosed by their physicians as being in the end stage of a terminal illness or disease, are aware of their diagnosis and have made a voluntary informed decision related resuscitation, and for whom the focus is palliation and not treatment aimed at cure.<sup>97</sup>

**Saskatchewan:** Palliative care is for patients who are in the late stages of a terminal illness: where life expectancy is measured in months, and for whom treatment aimed at cure or prolonging of life is no longer deemed appropriate, but for whom care is aimed at improving or maintaining the quality of remaining life (e.g. management of symptoms such as pain, nausea and stress).<sup>98</sup>

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<sup>96</sup> Ministry of Health, Government of British Columbia. BC Health Guide. [www.bchealthguide.org/kbase/topic/special/aa129753/sec1.htm](http://www.bchealthguide.org/kbase/topic/special/aa129753/sec1.htm). Accessed August 11, 2004.

<sup>97</sup> Alberta Health and Wellness. Palliative Drug Care Coverage (brochure). [www.health.gov.ab.ca/ahcip/prescription/80475.pdf](http://www.health.gov.ab.ca/ahcip/prescription/80475.pdf), Accessed August 11, 2004.

<sup>98</sup> Saskatchewan Health. Home Care (website). [www.health.gov.sk.ca/ps\\_home\\_care.html](http://www.health.gov.sk.ca/ps_home_care.html). Accessed August 12, 2004.



**Manitoba:** Palliative care is for patients in the final stages of a terminal illness, where the focus of care shifts to providing comfort and managing the symptoms of their illness.<sup>99</sup> Palliative care can include the patient's family. It may be offered in hospitals, a long-term care facility or at the patient's home.

**Ontario:** Ontario does not have a standard definition of end-of-life, palliative or hospice care; however end-of life care is recognized to include both palliative and hospice care and intended to alleviate suffering – physical, psycho-social or spiritual – rather than to cure.

Palliative care is a program of active compassionate care primarily directed towards improving the quality of life for the dying. It is delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, psychological, emotional, social, cultural and spiritual needs of both the patient and the family.

Hospice can have several meanings but generally, hospice care is provided by professionals or volunteers who deliver physical, spiritual or emotional support to individuals or families living with a life-threatening illness in the individual's home or wherever their current home might be, such as a long-term care facility, a retirement home or a supportive housing environment.<sup>100</sup>

**Nova Scotia:** There is currently no definition of end-of-life care in Nova Scotia.

**Prince Edward Island:** PEI does not use the term end-of-life but rather palliative care which the province defines as the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from a progressive life-threatening illness, or who are bereaved.

**Newfoundland Labrador:** Palliative care is defined as active compassionate care of the terminally ill at a time when symptom control is crucial and it includes the patient, family and community. Quality end-of-life care expands the concept of palliative care to include all end-of-life situations. The types of diseases covered and the period of time for which it is provided is expanded beyond cancer and the last few weeks of life.

**Yukon:** Palliative care services provide support for individuals who wish to receive end-of-life care in the home. Services are designed to alleviate symptoms and achieve the best quality of life. The distinction between palliative care and end-of-life care in this territory is that the former refers to services designed only for symptom management and comfort care, while the latter client group may be terminally ill but still want aggressive, active treatment.

**Northwest Territories:** Palliative care is the active, compassionate care of a person whose disease is no longer responsive to treatment aimed at cure. The goal of palliative care is to promote quality of life through control of symptoms whether they are physical, psychological, social or spiritual.<sup>101</sup>

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<sup>99</sup> Manitoba Health. Your Health Services: Palliative Care (website).

[www.gov.mb.ca/health/guide/2/palliative.html](http://www.gov.mb.ca/health/guide/2/palliative.html). Accessed August 12, 2004.

<sup>100</sup> Ontario Ministry of Health and Long-Term Care. Response to Quality End-of-Life Coalition Survey.

Reported in Quality End-of-Life Care Coalition. Dying for Care: Status Report, June 2004.

[www.chpca.net/quality\\_end-of-life\\_care\\_coalition\\_of\\_canada.htm](http://www.chpca.net/quality_end-of-life_care_coalition_of_canada.htm).

<sup>101</sup> Northwest Territories Health and Social Services. Home Care (website).

[www.yhssa.org/Library/pdfs/Palliative.pdf](http://www.yhssa.org/Library/pdfs/Palliative.pdf). Accessed August 12, 2004.

## **Appendix 10**

### **Current Federal/Provincial/Territorial End-of-life/Palliative Care Programs**

## **FEDERAL JURISDICTIONS**

### **Veterans Affairs Canada**

The actual benefits, services and care that VAC can provide must be based on the client's eligibility for health care programs as defined in the relevant chapters of the VPPM and in the *Veterans Health Care Regulations*. If a client's needs cannot be met through departmental programs, other community-based or provincial programs should be explored. VAC provides nursing, other professional services, drugs, medical equipment/supplies, personal care, assessment and case management depending on eligibility and availability of provincial programs. VAC policy identifies the components of the palliative care plan and, defines where the care may be provided and, who the care providers can be.

### **Indian and Northern Affairs Canada**

There are no services currently provided under the First Nations and Inuit Home and Community Care Program or the Assisted Living Program.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

### **British Columbia**

The BC Palliative Care Benefits Program supports individuals of any age who have reached the terminal stage of disease or illness and are facing the last months, weeks or days of their lives. Eligibility is determined by a physician, and includes those who have a life expectancy of up to six months and have consented to the focus of care as palliative and not treatment aimed at cure. In its October 2002 discussion paper,<sup>102</sup> the BC government committed to expanding home care and palliative care services for chronically and terminally ill patients. These services provide supportive home environments as an alternative to hospital care. The government has also committed to providing patients living at home, in palliative care, or in long-term care with the same drug benefits they would receive if they were in hospital, and to providing better home support and home care services. The BC Palliative Care Benefits Program,<sup>103</sup> which became effective on February 1, 2001, has two components: Palliative Care Drug Plan and the Medical Supplies and Equipment Benefits. The Palliative Care Drug Plan provides palliative care patients free prescription drugs and selected over-the counter (OTC) drugs needed for care and treatment at home. Eligible medications currently available under the BC Palliative Care Drug Plan include supplies needed for medication administration such as needles and syringes, and intravenous therapy supplies such as hydration solutions, tubing, catheters, syringes and needles.

### **Alberta**

The Alberta program provides premium-free coverage for patients who have been diagnosed as being palliative by a physician and are being treated at home. The program subsidizes the cost for eligible prescription medications, specific laxatives and solution for hydration therapy. The patient is responsible for 30 per cent of the cost of drugs to a maximum of \$25 per prescription, with a total out of pocket amount of \$1,000.<sup>104</sup> Regional Health Authorities in Alberta deliver palliative home care services through their community care services program.

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<sup>102</sup> Ministry of Health Services, Government of British Columbia. 2002. Discussion Paper on a Provincial Strategy for End-of-Life Care in British Columbia.

<sup>103</sup> Ministry of Health and Ministry Responsible for Seniors' Affairs, Government of British Columbia. 2001. BC Palliative Care Benefits Program. Program Description. February 1, 2001.

<sup>104</sup> Alberta Health. Health Care Insurance Plan And Services: Palliative Care Drug Coverage (website) <http://www.health.gov.ab.ca/ahcip/prescription/palliative.html>; and Palliative Care Drug Coverage (brochure). [www.health.gov.ab.ca/ahcip/prescription/80475.pdf](http://www.health.gov.ab.ca/ahcip/prescription/80475.pdf). Accessed August 11, 2004.

## **Saskatchewan**

Saskatchewan has a palliative care program for patients who have a life expectancy of a few weeks or months.<sup>105</sup> In 1998, the province decided that end stage palliative individuals would not be charged fees for home care services. In 2002, Saskatchewan decided that home care and palliative care be part of core primary health care services to be delivered by Regional Health Authorities on a 24/7 basis.<sup>106</sup>

Home care services include case management and assessment, nursing, therapies (in some areas), personal care, home management, meals, respite, minor home maintenance and volunteer services such as visiting, security calls and transportation. Home care fees are established based on income.

The Palliative Care Drug Plan Program provides access to free coverage of drugs on the province's drug formulary. The patient's pharmacy will bill the Drug Plan for 100 per cent of the cost of benefit medications. Coverage is also provided for some commonly used laxatives, on prescription request, to patients registered under this program.

## **Manitoba**

Manitoba has a palliative care sub-program (under Home Care). Each regional health authority has a palliative care coordinator for home care and services, both for home and hospital care. A person is eligible for services if their prognosis is less than six months, is referred by a physician, no longer receiving aggressive treatment, and has chosen a comfort-focused approach including a decision to decline attempted resuscitation. Services include medical and nursing care, prescription drugs, social, educational and spiritual care. The Palliative Care Drug Access Program publicly funds eligible prescription drug costs for palliative care patients in any setting.<sup>107</sup>

## **Ontario**

Community Care Access Centres provide nursing, occupational therapy, physiotherapy, social work, speech-language therapy and dietetic services at no cost to clients. Ontario provides respite services through CCACs, long-term care facilities and a direct funding program for medically fragile children. CCAC clients receive a provincial drug card but are required to pay a \$2.00 co-payment.

There have been a number of palliative care pilot projects in the province, including a Hospice for the Homeless in Ottawa, the first of its kind in Canada. The Hospice Palliative Care Network Project which ran between 1999 and 2001 offered access to a network of support for persons with an advanced illness who wished to remain at home or live in a LTC institution and their families. The team of providers includes palliative care physicians, nurse consultants, coordinator consultants and hospice volunteers.<sup>108</sup>

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<sup>105</sup> Saskatchewan Health. Home Care (website). [www.health.gov.sk.ca/ps\\_home\\_care.html](http://www.health.gov.sk.ca/ps_home_care.html) Accessed August 12, 2004.

<sup>106</sup> Saskatchewan Health, 2002. The Saskatchewan Action Plan for Primary Health Care. [www.health.gov.sk.ca/ph\\_phs\\_publications/phs\\_action\\_plan\\_for\\_primary\\_health\\_care.pdf](http://www.health.gov.sk.ca/ph_phs_publications/phs_action_plan_for_primary_health_care.pdf).

<sup>107</sup> Manitoba Health. Your Health Services: Palliative Care (website). [www.gov.mb.ca/health/guide/2/palliative.html](http://www.gov.mb.ca/health/guide/2/palliative.html) Accessed August 11, 2004.

<sup>108</sup> Canadian Home Care Association. 2003. Home Care and Palliative Care. *ibid*.

## **New Brunswick**

The New Brunswick Extra-Mural Program provides comprehensive home health care services to individuals of all ages for promoting, maintaining or restoring health, as well as providing palliative care to support quality of life for individuals with progressive-life threatening illnesses. The Extra-Mural Program is established within the Regional Health Authorities. Clients to the EMP must be referred by an attending physician or designate who has admitting privileges in the Regional Health Authority, with the exception of rehabilitation services to which individuals can self refer or be referred by any professional or agency.

The Extra-Mural professionals provide health care services that include: assessment, interventions (including treatment, education and consultation), service planning and coordination. Professional service providers may include: nurses, registered dietitians, respiratory therapists, occupational therapists, physiotherapists, speech language pathologists and where funded, social workers. Services offered include: acute care, palliative care, home oxygen program, long-term care assessment and rehabilitation services.<sup>109</sup> Approximately four to five per cent of EMP caseload receives palliative care. Clients who are in receipt of home health care services can access supplies and equipment. The EMP is the payer of last resort for drugs.<sup>110</sup>

## **Nova Scotia**

No information regarding palliative care was available on the Nova Scotia Health website. However, the Health Transition Fund supported a pilot palliative care project, A Rural Palliative Home Care Model: The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island.<sup>111</sup> The pilot took place in three sites. The project used rural primary care teams, supported by a regional mobile team, to provide palliative home care services. The project examined how to overcome barriers to service delivery, how to integrate palliative home care with other services and in a variety of settings, and how to support and educate providers.

## **Prince Edward Island**

Palliative care is publicly funded in PEI through global budgets to the four regional authorities and is delivered through their Home Care and Support Programs. Eligibility is not restricted to those who are expected to live less than six months. Publicly funded services included client assessment, case management, nursing, rehabilitation therapies, social work, adult protection, community support, dietitian, mental health, and essential personal care. Drugs and medical equipment and supplies are not publicly funded.

## **Newfoundland Labrador**

End-of-life care in the community is provided at various levels throughout the province. At present services are provided from home support funding allocated to seniors and clients with disabilities. This type of care involves a variety of skilled caregivers (such as social workers, doctors, and nurses) educated in the concepts of death and dying. Treatment modalities include a holistic approach to pain and symptom management that moves beyond a pharmacological dimension to include psychosocial, emotional and spiritual support. End-of-life-care is currently

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<sup>109</sup> New Brunswick Health and Wellness. Extra-Mural Program (website) [www.gnb.ca/0051/0384/index-e.asp](http://www.gnb.ca/0051/0384/index-e.asp) Accessed August 12, 2004.

<sup>110</sup> New Brunswick Health and Wellness. 2003. The New Brunswick Extra-Mural Program. Available at: [www.gnb.ca/0051/0384/pdf/1985e.pdf](http://www.gnb.ca/0051/0384/pdf/1985e.pdf)

<sup>111</sup> Health Canada. Health Transition Fund Project Fact Sheet NA013: Rural Palliative Home Care Project (website). [www2.itssti.hc-sc.gc.ca/B\\_Pcb/HTF/Projectc.nsf/FactSheets\\_e/5A8306836FBFA3358525660900418DA2](http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/FactSheets_e/5A8306836FBFA3358525660900418DA2).

available on a limited basis to clients in the community who are not in receipt of curative treatment, and the ability to provide service to these clients depends on the amount and type of intervention required. Case assessment and management are publicly funded. Nursing and allied health services are limited. Equipment is means-tested and supplies are provided on a limited basis. Personal care is means-tested and involves a co-payment. Drugs are not covered. Because there is not formalized program clients are not always aware of the service and Regional Boards are not funded to promote the service.

### **Yukon**

Based on the nature of need and a prognosis of less than six months, clients are provided a list of fully funded services from client assessment, case management, nursing, other professional services, drugs, supplies and equipment and essential personal care. In rural areas client assessment, case management, nursing and personal care are available without waits. Supplies and equipment are available but must be flown or trucked to the client. Intake processing for services only takes place between Monday and Friday.

**Northwest Territories:** NWT offers publicly funded home care services such as coordination of supplies, equipment and medication, coordination of home support workers, nurses, occupation and physical therapists, respiratory therapists, clergy, dietician, interpreters and volunteers, liaison with family physician, and support and education to caregivers on how to care for the patient, and adapt the living environment.<sup>112</sup> There are no user fees.

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<sup>112</sup> Northwest Territories Health and Social Services. Home Care. [www.yhssa.org/Library/pdfs/Palliative.pdf](http://www.yhssa.org/Library/pdfs/Palliative.pdf) Accessed August 12, 2004.

**Appendix 11**

**Best Practices in  
End-of-Life Care**

## **Alberta**

The Edmonton Regional Palliative Care Program (RPCP) began in 1995 and is a community based model of palliative care services. The program attempts to shift the main arena of end-of-life care from acute care, to home and hospice (hospices are in continuing or long-term care facilities). Previously, access to palliative care services was inconsistent and was provided largely in hospital. In 1992, 78 per cent of oncology patients died in acute care hospitals, with an average of 20,000 patient days per year. In 1999/2000, the number of acute care days was 7,639 a decrease of 14,979 patient care days. In 1999/2000, ten per cent of patients seen in the program (126/1273) were patients with other diagnoses. To accomplish this, services were enhanced in the home, hospice and consultation to allow the transfer of care to other settings.<sup>113 114</sup>

The components of care – home care and family physicians, outpatient clinics, palliative hospice, regional consultants, acute care (referral hospitals) and tertiary palliative care unit – are centrally coordinated by the regional office. Patients and their families have access to palliative care consultants regardless of the care setting. The program has criteria for admission for each level of care, assisting in the streamlining of care for patients.

## **Ontario**

An innovative model of home palliative care coordination and delivery called Hospice Palliative Care Network Project (HPCNet) began in April 1999. The HPCNET Project is a joint effort of Mount Sinai Hospital Palliative Care Centre and the Toronto Community Care Access Centre, working with a number of community organizations, the Philip Aziz Centre, Bayview Community Hospice, Casey House Hospice, Community CARE Home Hospice and Trinity Home Hospice, as well as the Ontario Ministry of Health and Long-Term Care. Services include pain and symptom management, case management, consultation services to primary caregivers, and practical and emotional support.

It is an objective of the Project that every palliative care patient within the test area is seen by a palliative care physician and has access to nursing, home care, hospice services, and volunteer services. The specific goals of the HPCNet Project are to:

- Coordinate the interdisciplinary palliative care consultation services of community-based care providers, agencies, and health care institutions;
- Refer and identify problems early;
- Develop uniform, evidence-based assessment tools for use during the initial consultation and in the daily care of patients and their families;
- Enhance the role, knowledge base and skills of physicians, nurses, home care coordinators, and volunteers who provide palliative care services.

The three Project teams have cared for more than 4,000 patients in the old city of Toronto since the Project began. Each of these patients has had access to the services of a specialist palliative care consultant physician, nurse, care coordinator, and hospice volunteer. Approximately 60 per cent of HPCNet patients are able to remain at home to die.

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<sup>113</sup> Capital Health (Alberta) Region. Regional Palliative Care Program: Annual Reports 2000-2001 and 2001-2002. [www.palliative.org/PC/RPCP/annual%20report%2001%20&%20%2002.pdf](http://www.palliative.org/PC/RPCP/annual%20report%2001%20&%20%2002.pdf).

<sup>114</sup> Capital Health (Alberta) Region. Regional Palliative Care Program (website). [www.palliative.org/PC/RPCP/RPCPIIdx.html](http://www.palliative.org/PC/RPCP/RPCPIIdx.html) Accessed August 10, 2004.



Education is a core element of the consultative model. Team members have been working with primary care providers in the home and through formal education initiatives. The project has also developed patient education material produced in different languages.

A common patient chart, the Record of Care, has been developed in collaboration with 33 nursing, hospice and homemaking agencies and has proven to be vital to collaboration, communication, and the development of integrated goals and care planning. The ROC has also been translated into French, through the support of the Toronto District Health Council. Caregivers (including physicians, nurses, care coordinators, counselors, and hospice coordinators) use hand-held computers in the community. This has helped to build a database with remote access interface.

Evaluation of the model has been ongoing throughout the Project both by the Project committee and an external evaluator.<sup>115</sup>

In 2001, the Mission in Ottawa opened an eight-bed hospice, the first palliative care home linked to a shelter for the homeless. The commitment grew out of a growing number of requests from clients who wanted to die in the shelter, which they considered home. The hospice is open to both men and women and can service approximately 50 people a year. Care is provided 24 hours a day, seven days a week.<sup>116 117</sup>

### **Quebec**

Quebec has specialized services such as intravenous therapy, home chemotherapy and palliative care coordinated by its Local Community Service Centres (CLSC). Between 1998 and 2000, the Health Transition Fund supported a palliative care initiative, *Toward a Continuum in Care and Services for Terminally Ill Adult Users*.<sup>118</sup> A partnership of five Montreal CLSCs provided on-call nursing, medical and drug services, home care services, a dedicated phone line, and psychological, social and bereavement support. Some of these services were available around the clock. Patients had access to day hospitals as well. These CLSCs prior to the project had about five to 10 per cent of their terminally ill clients receive palliative care, the majority of whom were cancer patients. One result of this project was that 30 per cent of cancer patients received palliative care. Moreover, over 50 per cent of patients died at home, a rate much higher than the provincial rate. The project produced much better quality of life and physical health for family caregivers. The project demonstrated the benefits of comprehensive palliative care services delivery by multidisciplinary teams.<sup>119 120</sup>

### **Nova Scotia/PEI**

Evaluation of the Rural Palliative Home Care model project revealed that clients and caregivers were generally satisfied with the care provided, and especially its improved coordination. Factors that contributed to the success of the model included: collaboration among disciplines and agencies; common standards for care; a single access point for services; a clinical team with

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<sup>115</sup> Mt. Sinai Hospital. Hospice Palliative Care Network Project (HPCNet) (website). [www.tlcpc.org/hpcnet/index.php](http://www.tlcpc.org/hpcnet/index.php).

<sup>116</sup> "John Ralston Saul opens first hospice for homeless in Canada" (news release, Ottawa, May 29, 2001). [www.media.uottawa.ca/mediaroom/news\\_details-e.php?nid=124](http://www.media.uottawa.ca/mediaroom/news_details-e.php?nid=124).

<sup>117</sup> Caledon Institute for Social Policy, 2001. *Taking Health Care to the Streets*. Available at: [www.caledoninst.org/Publications/PDF/894598997.pdf](http://www.caledoninst.org/Publications/PDF/894598997.pdf).

<sup>118</sup> Health Canada. Health Transition Fund (website). [www.hc-sc.gc.ca/htf-fass/english/](http://www.hc-sc.gc.ca/htf-fass/english/).

<sup>119</sup> Canadian Home Care Association, 2003. Home Care and Palliative Care. *ibid*

<sup>120</sup> Health Canada. Health Transition Fund. *ibid*..

expertise in palliative care; and coverage for medications in cases of financial need (Nova Scotia site only). Barriers to developing a fully integrated program included a lack of 24-hour access to referral services; funding for respite and nursing visits (Prince Edward Island sites only); a funding formula to reimburse physicians for palliative-care services; and an integrated information system.

### **Prince Edward Island**

In addition to the Rural Palliative Home Care Model project, PEI has implemented West Prince Telehospice, a pilot project, which is to provide support to a dying person at home 24 hours per day. Using a telephone line and fully interactive audio visual equipment, nurses and other health professionals can monitor and assess the health/vital signs of clients and provide education to clients living at home. Results have shown a 76 per cent decrease in days that dying clients were hospitalized, a 20 per cent reduction in emergency room use, and 15 per cent reduction in physician office visits.<sup>121</sup>

Despite the variation, there appears to be impetus both at the national and provincial/territorial level to improving end-of-life care. There is considerable innovation at the local level. A number of pilot projects outlined above provide models for the delivery of integrated, quality palliative care. Model elements that appear to contribute to cost-effective, accessible, quality care with greater client satisfaction include 24-hour access to multidisciplinary provider teams, integration across the continuum of health, access to all home care services including full coverage for drugs, supplies and equipment. The use of technology in the home also needs further exploration.

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<sup>121</sup> Canadian Home Care Association. 2003. Home Care and Palliative Care. *ibid.*

## **Appendix 12**

### **Review of Federal/Provincial/Territorial Use of Assessment Tools and Formats for Home Care**

## **FEDERAL JURISDICTION**

**Health Canada:** Health Canada supports the use of comparable assessment tools, not necessarily common assessment tools across jurisdictions.

**Veterans Affairs Canada:** VAC has developed a number of comprehensive assessment tools which are used to support case management and service delivery. General assessment tools for collecting baseline data on the client are used in addition to detailed nursing, occupational therapy and medical assessments. Optional tools, e.g. the Folstein MMSE, Geriatric Depression Scale (GDS) and the Power Mobility Assessment Tool are shared instruments. VAC has recently implemented, via web-enabled technology, a process whereby health professional assessments which are completed by external providers on a fee-for-service basis, can be requested, completed and returned to VAC on-line, and then, once approved by the Departmental Nurse or OT, entered into the VAC electronic client record.

**Indian and Northern Affairs Canada:** Each community is required to use an assessment tool; however, the tools vary across the country. Some communities choose to use the provincial assessment tool, others have developed their own assessment tools. At the present time the majority of communities are using paper-based assessment tools. The First Nations and Inuit Health Branch is just commencing national piloting of an electronic web-based Home and Community Care application that contains both a triage assessment tool and a number of in-depth assessment screens. This has also been developed to operate in a disconnected mode to enable data entry on a laptop in the home and then uploaded back at the office. The FNIHCC program receives aggregate community program data from an electronic Service Reporting Template that has been deployed to over 50 per cent of FN/I communities across the country. Tribal Council, Regional and National electronic generated reports will commence this fall and will be sourced from the community aggregate reports. For the Assisted Living Program, the majority of communities at the present time are using paper-based assessment tools. However, the department is involved in two initiatives to ensure a future electronic assessment platform.

## **PROVINCIAL/TERRITORIAL JURISDICTIONS**

**British Columbia:** The mini mental status exam (MMSE) and a financial assessment (LTC1.6) were added to the LTC1 to form the comprehensive assessment instrument used in BC. However, the InterRAI tools for home care (by 2005) and residential care (by 2007) have been mandated for use by health authorities. Clinical data is tracked through computerized and manual systems.<sup>122</sup>

**Alberta:** Alberta uses the Alberta Assessment and Placement Instrument (AAPI) which was introduced in 1990. Clinical data is tracked manually. Each RHA has its own system for financial data. All administrative data reporting to Alberta Health is on the Home Care Information system.<sup>123</sup>

**Saskatchewan:** Regional Health Authorities in Saskatchewan use the Saskatchewan Client Information Profile (SCIP) as the assessment tool for home care. The SCIP assessment tool is paper form but is moving to an electronic platform. The assessment tool may be used for all three Accord streams but may be limited in use for acute community mental health care. Many of

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<sup>122</sup> Canadian Home Care Association (CHCA). 2004. *Portraits of Home Care. A Picture of Progress and Innovation.*

<sup>123</sup> CHCA. *ibid.*

the elements in the SCIP are similar to the RAI-HC elements. Currently the province is working to implement the Minimum Data Set (MDS) Home Care tool, which is a standardized assessment and classification tool that is RAI compliant. In addition, Regional Health Authorities in Saskatchewan are starting to implement the Procura system for the business aspect of home care, i.e. scheduling, billing, service plan.

**Manitoba:** The Winnipeg Region uses the RAI-HC but the rest of the province uses a standard Home Care assessment tool. A short-term Home Care assessment form is used by Home Care staff in the hospital prior to discharge. With reference to acute community mental health, there is no common assessment tool. While Winnipeg uses an electronic platform for assessment, the rest of the province uses paper forms.

**Ontario:** Ontario uses the RAI-HC for home care clients. It is piloting the InterRAI-CHIP (Community and Hospital Intake Profile), a triage system. One of its purposes is to provide a basic assessment of short-term service clients (rehabilitation and medical) who would *not* be receiving any additional assessment at a later stage. An interim electronic system for the RAI-HC is in place for clinical data. A computer system (ACPAC) is used to track financial data but a system is being developed to support the implementation of MIS reporting standards. Three different computer systems are used throughout Ontario. PMI is used by 32 CCACs; CMIS is used by four CCACs; CARE is used by five CCACs; and OASIS is used by one CCAC.<sup>124</sup>

**Quebec:** The standardized Évaluation, Multi-Clientèle (EMC) tool is used for elderly clients, adults with disabilities for long-term care, home care and foster care. Clinical data is tracked both electronically and manually. It is anticipated that the EMC will be computerized soon.<sup>125</sup>

**New Brunswick:** No information on an assessment tool was available. For most of the province a web-enabled tool is in development for clinical data. The Extra Mural Program uses Meditech for financial data tracking and a provincial information system for administrative data.<sup>126</sup>

**Nova Scotia:** Nova Scotia uses a common assessment tool, RAI-HC, for clients with an expected length of stay in the program of greater than 30 days. It does have common assessment tools for acute and palliative care. These tools have common data elements which are compatible with RAI-HC. Clients with an expected length of stay in the program of less than 30 days are assessed using an alternative tool, which does not have common assessment tools for acute and palliative assessment and is not compatible with RAI-HC. The province uses both electronic (RAI-HC) and paper assessment platforms. The paper assessment tool is used for clients with an expected length of stay in the program of less than 30 days. The paper assessment is not transposed into electronic records and is not compatible with the RAI-HC.

**Prince Edward Island:** PEI uses the Seniors Assessment and Screening Tool (SAST) in its Home Care and Support Program. There is also a common assessment tool used for palliative care. It currently uses both a paper and electronic assessment platform and transposes the data collected on paper into an electronic format.

**Newfoundland/Labrador:** The province has standardized home support tools to assess the needs of seniors and clients with disabilities. Although this tool measures functional capacity, it is

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<sup>124</sup> CHCA. 2004. *ibid.*

<sup>125</sup> CHCA. *ibid.*

<sup>126</sup> CHCA. *ibid.*

not compatible with RAI-HC elements. Currently assessments are done on paper and are not transposed into an electronic format.

**Yukon:** Yukon uses the RAI-HC. Although training on the use of the RAI-HC is completed, the territory is not using the full RAI-HC tool but rather an interim version. Although clients are assessed electronically, the assessments are not stored in electronic format due to current incompatibilities with GoldCare, the territory's computer system. Rather, copies of the electronic assessment are printed and a hard copy is placed in the client's file.

**Northwest Territories:** The NWT uses the Continuing Care Assessment Package. The territory uses both paper and electronic information systems, with data from the former being transposed into electronic records.

**Nunavut:** No information on an assessment tool was available. Clinical and administrative data are tracked manually, while financial data is computerized.<sup>127</sup>

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<sup>127</sup> CHCA. 2004. *ibid.*