Strengthening home and community care across Canada: A collaborative strategy

Report to the Annual Premiers' Conference August 2002

Table of Contents

Executive Summary

At the January 2002 meeting in Vancouver, Premiers noted that they were all increasing investments in continuing care and noted increased quality benefits. In the absence of the federal government meeting its commitment to fund improvements, Premiers committed to developing a coordinated long term care response for the Annual Premiers' Conference in August 2002[1]. This approach would shift the focus from seeking consensus on a national vision for home and community care, to promoting real and meaningful change based on the identification of concrete strategies for action.

Currently, all provinces/territories are increasing expenditures on their home and community care systems in response to the growing and changing demands impacting on the sector. The pressures being placed on the home and community care sector are representative of the kind of pressures provinces/territories are facing in responding to changes in the health sector and addressing the growing demands being placed on their health care systems. Over the past two decades, expenditures on home and community care have grown from $205 million to $2.7 billion,[2] an increase of over one thousand percent. This translates to an average annual rate of 21.3 percent, greatly out-stripping overall health spending and general inflation.[3] Home and community is a growing and increasingly important component of the health system, comprising 4.25 percent of the overall spending on health care within provincial budgets, whereas it made-up only 1.25 percent of health spending 20 years ago.[4] The health aspects of home and community care are a provincial responsibility, fully funded by the provinces and territories, and responsive to jurisdictional circumstances and priorities.

Pressures to further increase resources in this area are expected to continue as the sector struggles to adapt and respond to a number of changes, namely:

- Growing expenditures as a result of consumer preferences, acuity changes, growing reliance on the sector, an aging population, and health care reform;
- Changing profile of users in many provinces/territories;
- Increasing acuity/complexity of client caseload as changes in delivery allow more treatment interventions at home versus in hospital;
- Continued movement from facility-based to home and community-based care
- Changing public-private mix and increasing availability of private services;
- Changing and growing human resource pressures;
- Expanding use of in-home medical technology to improve service delivery;
- Strengthening data and information systems for program planning and evaluation.

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[1] Canadian Intergovernmental Conference Secretariat (2002). *Provinces Pave the Way for the Future of Health Care.* Provincial -Territorial Premier's Meeting Vancouver, British Columbia. January 24 –25, 2002. www.scics.gc.ca/cinfo02/850085004_e.html News Release Ref. 850 –085/004

[2] Health Canada, *Health Expenditures in Canada by Age and Sex, 1980-81 to 2000-01*. See www.hc-sc.gc.ca/english/care/expenditures.htm

[3] Coyte, P.C. and W. Young, *Reinvestment in and Use of Home and community care Services.* Pub. No. 97-95 (Toronto: Institute for Clinical Evaluative Sciences, 1997).

[4] Health Canada, *Health Expenditures in Canada by Age and Sex, 1980-81 to 2000-01*. See www.hc-sc.gc.ca/english/care/expenditures.htm

The definition of home and community care that was developed and adopted for the purposes of this paper is:

> Home and community care is the provision of health care, community and social support programs that enable individuals to receive care at home and/or live as independently as possible in the community. A number of provinces refer to their home and community care programs as a component of the continuing care system.[5]

Home and community care programs serve a diverse clientele, considering factors such as age, health status, medical and social needs, functional status, the duration of services and the availability of caregiver supports.

This report identifies a shared plan of action that will help provinces/territories respond individually and collectively to address key issues confronting the home and community care sector and to strengthen its role within the care continuum. The strategies identified as part of the plan of action build on the common interests and collective experiences of provinces/territories.

Strategies to Strengthen Provincial/Territorial Home And Community Care Programs	
Strategy 1	Supporting caregivers
Strategy 2	Expanding use of in-home technologies to improve home and community care delivery to benefit clients, caregivers, and providers
Strategy 3	Expanding new models for home care in supportive living arrangements
Strategy 4	Achieving better integration between home and community care and other parts of the health care system
Strategy 5	Improving quality and availability of information on home and community care services

The strategies proposed as part of the plan of action are not intended to be prescriptive. Rather, they set out a framework that provides provincial/territorial leaders with a focal point to come together, to share expertise and to build on each other's experiences to strengthen the capacity of the home and community care systems across the country. While there is increasing recognition of the potential value of sharing experiences and information, there is also a strong commitment to maintaining the appropriate levers and supports at the provincial/territorial level that will respect the diversity and complexity of home and community care programs across the country.

Consideration of the current trends, drivers of change, and identification of the strategies included in the plan of action, led to the following recommendations. That provinces/ territories work together to:

[5] In Quebec, home and community care services are part of the primary care system.

(1) Explore options that will provide support and assistance to family and other caregivers who care for people in the home. Options could include flexible work arrangements, elder care leave, respite care, and training and education required to support caregivers in their role.

(2) Identify approaches to facilitate broader adoption of technology for use in home and community settings with a focus on expanding and enhancing:
- **The use of medical and equipment technologies to support in home services; and**
- **Telehealth technologies to assess, treat and monitor clients, and provide client and caregiver training and education.**

(3) Support collaboration between home and community care and housing providers to develop innovative and affordable supportive living and other facility arrangements. These arrangements should:
- **Build on the successful implementation of supportive living models in a number of provinces;**
- **Consider the benefits to be acquired through public-private partnerships; and**
- **Include communication strategies that promote the advantages of supportive living to the public and providers.**

(4) Examine approaches that will improve the continuity of care for the client by enhancing coordination and linkages between:
- **Home care providers;**
- **Home care providers and other health care providers (in acute care, primary care and long-term care sectors); and**
- **Home and community care information with other health information to improve client care.**

(5) Collaborate to identify common data elements across provinces/territories that will:
- **Promote consistent classification of clients;**
- **Allow for comparison of home and community care client services and outcomes;**
- **Lead to better research and evidence-based decision-making; and**
- **Provide for linkages with other settings/levels of care.**

While innovations exist in the home and community care sector, there is a misperception that there is consensus on what constitutes best practices. This is not the case, and information pertaining to client needs, home care programs, and outcome data is necessary to identify strengths and weaknesses of home and community care programs and to discover and disseminate best practices in this area.

The five strategies identified in the plan of action represent specific areas where provinces/ territories believe they can be more effective individually by working collectively. The extent of collaboration regarding implementation of the strategies, however, will vary depending on the strategy. The next steps required to further the plan of action are for provinces/territories to:

- Determine individual priorities for each strategy based on the needs and characteristics of their jurisdiction.

- Share information and collaborate to move strategies forward.

- Leverage the strengths of the projects and experiences of provinces/territories to identify best practices in each of the strategic areas (i.e., targeted identification of things working well that other jurisdictions could build on/benefit from).

- Determine what constitutes 'best practices' related to each strategy.

- Identify specific initiatives that will advance (both individually and collaboratively) each of the strategies by each jurisdiction.

- Collaborate to identify priorities for future research to identify and build on international best practices in home and continuing care over the long term.

This report calls for a strengthened focus on home and community care. It builds on the belief that there is strong potential in provinces/ territories to collaborate around common strategies and build upon existing capacity and experiences to avoid duplication between jurisdictions and work toward identification of 'best practices'.

Provincial/territorial collaboration around the specific strategies identified in this report would go a long way to developing and sharing best practice information about what types of innovation work (and which don't). Partnerships among the provinces/territories to advance work in these areas would also help develop, where appropriate, strategic communication initiatives and collaborative research agendas that will yield new information and set priorities for future planning within the sector.

Part 1: Agreeing on a Plan of Action

- In January 2002, provincial and territorial Premiers discussed the challenges being confronted in their health care systems and agreed upon priority issues and areas for collaborative work. They noted that they were all increasing investments in continuing care and noted increased quality benefits. In the absence of the federal government meeting its commitment to fund improvements, Premiers will be developing a coordinated long term care response for the Annual Premiers' Conference in August 2002.[6]

- At that meeting, Premiers also confirmed that they had all increased investments in home and community care and that the sector was playing a growing role in their health care systems. [7]

- They also agreed that the work must shift from seeking consensus on a national vision for home and community care, to one that promotes real and meaningful change based on provincial/territorial collaboration around concrete strategies.

- This report outlines a provincial/territorial plan of action for moving the home and community care agenda forward.

Background and Context

- There is no issue that embodies the meaning of health reform more than the shift from facility-based care to home and community-based care. The changes taking place in health care across the country have made the home and community care sector an increasingly important and growing component of Canada's changing health service delivery systems.

- Demographic shifts in the population, changing public expectations, technological and scientific advancements in the delivery of health care, and continued movement from facility-based to home and community-based care are the major factors that are expected to contribute to continued growth and change within the sector.

- The pressures being placed on the home and community care sector are representative of the kind of pressures provinces/territories are facing in responding to changes in the health sector and addressing the growing demands being placed on their health care systems.

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[6] Canadian Intergovernmental Conference Secretariat (2002). *Provinces Pave the Way for the Future of Health Care.* Provincial -Territorial Premier's Meeting Vancouver, British Columbia. January 24 –25, 2002. www.scics.gc.ca/cinfo02/850085004_e.html News Release Ref. 850 –085/004

[7] Some jurisdictions, including Yukon, the Northwest Territories and Nunavut recognize investments made by the Federal Government to support home and community care programs for Aboriginal populations on and off reserve.

Purpose of this Report

- The purpose of this report is to develop some concrete strategies that can be pursued individually and collaboratively by the provinces/territories to address key issues confronting the home and community care sector and to strengthen its role within the care continuum.

- The overriding objective is to determine what kind of collaboration and provincial/territorial leadership will build upon existing services and confront the pressing issues in the current home and community care sector to promote comparable outcomes across provinces/ territories while allowing for flexibility in the design and implementation of local initiatives.

- The strategies proposed as part of the plan of action are not intended to be prescriptive. Rather, they set out a framework that provides provincial/territorial leaders with a focal point to come together, to share expertise and to build on each other's experiences.

> *"The reality is that no one gives much thought to home care until they are thrust into a crisis. And there is no telling when you will need help, when a family member will be felled by a stroke, consumed by dementia, immobilized by a broken hip or gripped by cancer."*
> Executive Director, Family Caregivers' Network Society, The Globe and Mail
> March 20, 1999

Definition

- The definition of home and community care that was developed and adopted for the purposes of this paper is as follows:

  Home and community care is the provision of health care, community and social support programs that enable individuals to receive care at home and/or live as independently as possible in the community. A number of provinces refer to their home and community care programs as a component of the continuing care system.[8]

Characteristics of the Current Home and Community Care System

- There is variation across the country with respect to home and community care funding, policies, services and delivery.

- For the most part, home and community care programs across the country provide three main functions:

[8] In Quebec, home and community care services are part of the primary care system.

1. A *substitution function* for services provided by hospitals and long-term care facilities;
2. A *maintenance function* that allows clients to remain independent in their current environment; and
3. A *preventative and monitoring function* that invests in client service to prevent deterioration in health (with expectations of additional short-run costs and lower long-run costs).[9]

- Home and community care programs serve a diverse clientele, considering factors such as age, health status, medical and social needs, functional status, the duration of services and the availability of caregiver supports.

- The health aspects of home and community care are a provincial responsibility, fully funded by the provinces and territories, and responsive to jurisdictional circumstances and priorities.

- Most provinces/territories have improved the coordination and integration of services offered as part of their home and community care services by putting in place a single point of access to promote comprehensive needs assessment, case management, and access to long-term facility-based care, including care for respite purposes.

- Many home and community care programs are experiencing a change in caseload with the focus in many provinces/territories shifting from accommodating the needs of long-term clients to short-term clients being discharged from acute care facilities. On average, 27 percent of clients are receiving short-term or acute services (although definitions vary by province), and 70 percent are receiving chronic or long-term services. Approximately 10 percent receive other types of services, which may include palliative care.[10]

Home and Community Care: A Sector Under Pressure

In spite of increased spending by provincial/territorial governments on home and community care across Canada in recent years, there is a growing belief that the sector remains under-funded, under-valued and over-stressed.[11] These pressures are the result of a redefinition of the home and community care sector that is occurring in response to reforms under way in the broader health care systems as well as to changes taking place within the sector itself.

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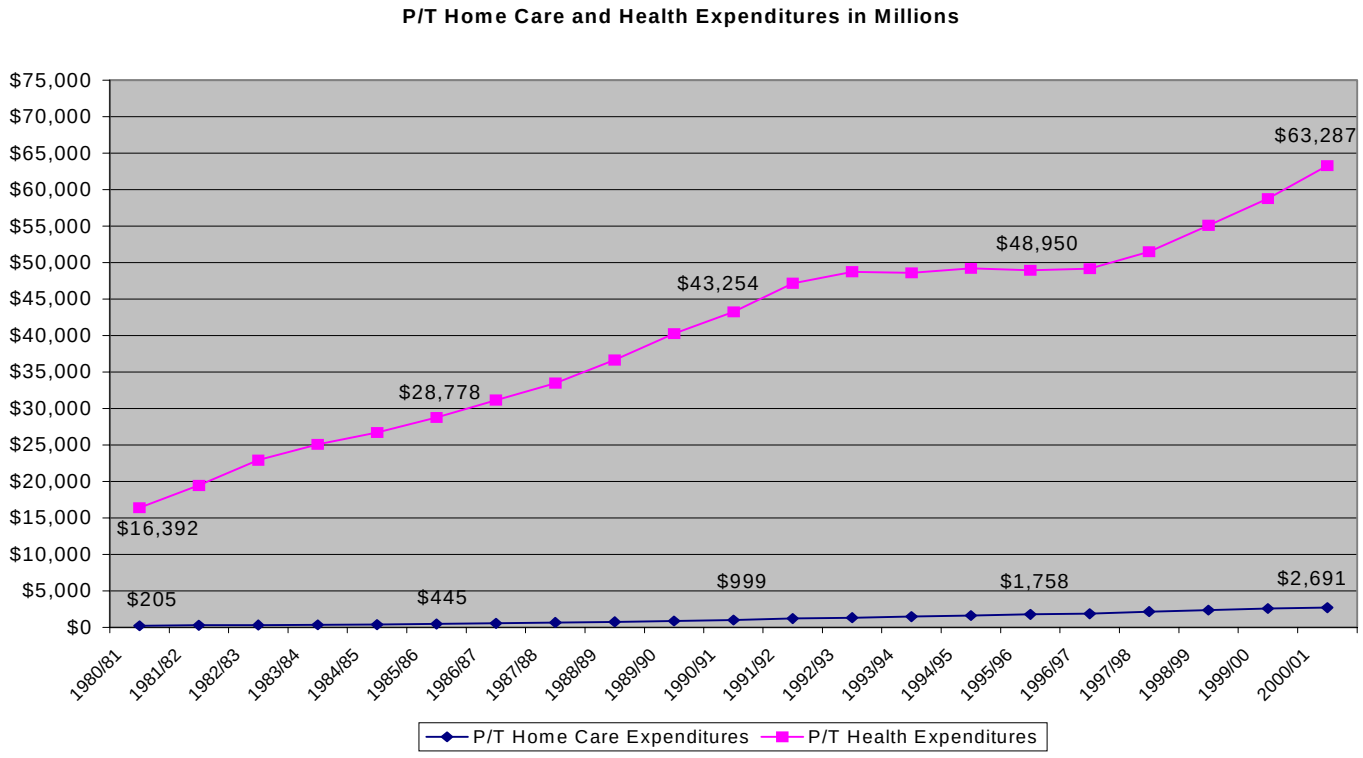
[9] The Canadian Home Care Association in collaboration with l'Association des CLSC et des CHSLD du Quebec (February 1998). *Portrait of Canada: An Overview of Public Home and community care Programs.* p. 1. See www.cdnhomecare.on.ca/e-info.htm

[10] Based on a survey of provinces and territories conducted for this report

[11] *Canadian Home Care Human Resources Study Phase 1 Highlights – Setting the Stage: What Shapes the HomeCare Labour Market.* December 4, 2001. See www.homecarestudy.ca

- From a **funding perspective**, the amount of money being spent by provincial and territorial governments on home and community care across the country is growing significantly. In 2000/01, home and community care accounted for 4.25 percent of the overall spending on health care within provincial budgets, whereas it made-up only 1.25 percent of health spending 20 years ago. However, this still represents a small amount when compared to provincial health spending in other areas (e.g., drugs at 7 percent or hospitals at 44 percent).[12]

- Over the past two decades, expenditures on home and community care have grown from $205 million to $2.7 billion[13], an increase of over one thousand percent. This translates to an average annual rate of 21.3 percent, greatly out-stripping overall health spending and general inflation.[14] However, the rate of growth has declined in the past five years to 8.9 percent, while private spending has almost doubled in this area.[15]



[12] Health Canada, *Health Expenditures in Canada by Age and Sex, 1980-81 to 2000-01*. See www.hc-sc.gc.ca/english/care/expenditures.htm
[13] Ibid
[14] Coyte, P.C. and W. Young, *Reinvestment in and Use of Home and community care Services*. Pub. No. 97-95 (Toronto: Institute for Clinical Evaluative Sciences, 1997).
[15] Coyte, P.C., *Home Care: Potentials and Problems*. Presentation given at Diagnostics and Solutions: Building Consensus for Health Care Reform in Canada. See www.hcerc.org

- From a **utilization perspective**, home care is one of the fastest growing and changing fields in the health care sector. The reasons for growth are related to the changes underway in the broader health care systems, the increase in our ability to treat chronic diseases and provide a variety of treatment interventions in the home, as well as a number of other important drivers of change.

- From a **cost-effectiveness perspective**, recent studies have found that home and community care is more cost-effective for certain types of client care:

    - In terms of long-term facility care, one study found that overall, home care costs are less than residential care and provide at least an equivalent quality of care. Proportionally, savings are greater at the lower levels of care.[16]

    - Research regarding the cost-effectiveness of home care as a substitute for acute care has been mixed. In a study that compared the provision of intravenous therapy for cellulitis patients at home and in hospital, home care and emergency services cost about half as much as care in the hospital and clients in home care and emergency had fewer complications and higher problem resolution rates.[17]

    - A study that examined the costs of a community-based *Quick Response Program*, which redirected clients who would otherwise be admitted to hospital from the emergency department back to their homes, was found to be effective.[18]

The Drivers of Change

Growing expenditures in the home and community care sector: Between 1975 and 1992, expenditures on home care grew twice as fast as total health spending (19.9 percent vs. 10.8 percent). Since 1992, expenditures have grown at three times the pace. In 2000/01, the national average per capita expenditures on home and community care was $87.51.[19] Despite its growth, home care still accounts for only one out of every twenty dollars governments spend on health.[20]

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[16] *The National Evaluation of the Cost-Effectiveness of Home Care, Substudy 1: The Comparative Cost Analysis of Home Care and Residential Care Services.* See www.homecarestudy.com

[17] *The National Evaluation of the Cost-Effectiveness of Home Care, Substudy 11: An Economic Evaluation of Hospital-Based and Home-Based Intravenous Antibiotic Therapy for Individuals with Cellulitis.* See www.homecarestudy.com

[18] *The National Evaluation of the Cost-Effectiveness of Home Care, Substudy 14: Evaluation of the Cost-Effectiveness of the Quick Response Program of Saskatoon District Health*. See www.homecarestudy.com

[19] Coyte, P.C., *Home Care: Potentials and Problems*. Presentation given at Diagnostics and Solutions: Building Consensus for Health Care Reform in Canada. See www.hcerc.org

[20] Commission on the Future of Health Care in Canada (May 2002*). Homecare in Canada – Discussion Paper*. A discussion document and survey on home care developed as one of a series of documents the Commission on the Future of Health care in Canada developed in partnership with the Canadian Health Services Research Foundation. p. 2

Between 1999 and 2026, home care expenditures are predicted to jump almost 80 percent. [21] The increases in provincial/territorial expenditures on home and community care are attributable to a number of factors, including:

- **Volume changes**: Demographic pressures and consumer preferences resulting in an increase in the number of individuals qualifying as eligible for home and community care.

- **Acuity changes:** Changing mix of clients; increasing acuity levels; need for more varied health care interventions, drugs, equipment and supplies; and technological advances and changes in delivery of care that allow more treatment interventions at home versus in hospital.

- **Growing reliance on the sector**: Home and community care is perceived as a lower cost alternative for some acute and long-term facility services.

- **An aging population:** According to Statistics Canada, 12.6% of the Canadian population is 65 or older,[22] and this is projected to rise to 18.8% by 2021.[23] It is estimated that close to one-third of people between the ages of 65 and 74 are limited in their daily functioning; this figure rises to 45 percent of those 75 and older.[24] On average, 64 percent of current home care clients are over 65 (45 percent of this group is over the age of 75).[25]

- **Health care reform**: Growing shift to care at home to support hospital, long-term care and other health system reforms.

Changing profile of users in many provinces/territories: A number of provinces/territories have seen changes in the clients who need home care and the services that they require. For example, technologically dependent children who would previously have been cared for in facilities are now living at home with home care support. People with disabilities and chronic illness are living longer and remaining in their homes. Patients are receiving earlier discharge from acute care facilities or are having day procedures and are seeking access to home and community care services.

In order to respond to these new demands, some home and community care programs have had to change their service mix to accommodate increases in acuity of care for short-term clients; decrease service levels for long-term clients; and decrease services for preventive and maintenance care.

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[21] Ibid
[22] Statistics Canada. *Population by sex and age*. http://www.statcan.ca/english/Pgdb/People/Population/demo10a.htm
[23] Statistics Canada. *Population projections for 2001, 2006, 2011, 2016, 2021, and 2026, July 1.* See http://www.statcan.ca/english/Pgdb/People/Population/demo23a.htm
[24] Armstrong, P., Armstrong, H., Choinière, J., Feldberg, G. & White, J. (1994). *Take care. warning signals for Canada's health system.* Toronto: Garamond Press.
[25] Based on a survey of provincial/territorial data conducted for this report

Increasing acuity/complexity of client caseload: A recent survey undertaken by Canada's Association for the Fifty-Plus (CARP) found that 89.7 percent of home and community care service providers feel that the complexity of care has increased over the past 3 years.[26] This trend is associated with increases in day surgery within the acute care sector, changes taking place within the long-term care sector, as well as a range of intensive and sophisticated services and equipment that are available to care for children and adults with complex medical and/or developmental needs.

Changing public-private mix and increasing availability of private services: In 1994, it was estimated that 90 per cent of home and community care services in Canada were provided by publicly-funded home and community care programs.[27] In many provinces, more private services are being offered to assist clients who are not eligible for publicly-funded home and community care and/or to make services available for those who wish to complement the public services they are receiving. It is important to note, however, that the option to access private services varies significantly across the country depending on their availability.

Changing and growing human resource pressures: The provision of home and community care services is carried-out by both regulated professionals and unregulated health workers.[28] In many provinces/territories, meeting the needs of a growing number and wider variety of home and community care clients has resulted in challenges related to skill mix, management, and wages for both these groups. Several provinces/territories are faced with trying to address shortages of nurses and a range of other home and community care workers in both rural and urban areas. This is even more problematic when seeking staff with specialized skills for specific client populations (e.g., mental health, pediatrics). Retention is also a key issue confronting the sector. This is linked to high rates of staff turnover within the sector as well as poor working conditions and a lack of competitive compensation and varying wage scales (especially for home support workers) relative to workers employed by hospitals and long-term care organizations in many provinces/ territories.[29]

Expanding use of in-home medical technology to improve service delivery: Today, the availability of sophisticated medical equipment allows for complex medical needs to be addressed in the home. Although procedures like home-

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[26] Parent K, Anderson M (2001). *CARP's Report Card on Home Care in Canada 2001. Home Care by Default Not by Design.*

[27] The Canadian Home Care Association in collaboration with l'Association des CLSC et des CHSLD du Quebec (February 1998). *Portrait of Canada: An Overview of Public Home and community care Programs.* See www.cdnhomecare.on.ca/e-info.htm

[28] Some home and community care services are delivered by health professionals; however, the bulk (70-80%) is provided by unregulated home support workers. See *Canadian Home Care Human Resources Study Phase 1 Highlights – Setting the Stage: What Shapes the HomeCare Labour Market*. December 4, 2001. www.homecarestudy.ca

[29] Health Canada.Home Care and Pharmaceutical Division. *Human Resource Issues in Home Care in Canada: A Policy Perspective.* See www.hc-sc.gc.ca/homecare/english/hr1.html

based dialysis and infusion are now possible in the home, they require more highly-skilled staff to provide the more complex care and, in some cases, shift the financial costs to the client when performed outside of the hospital (e.g., equipment and drug costs).

Technology also supports the use of telephone lines for tele-home care, allowing virtual home care visits, video conferencing with specialists and long distance education to clients and professionals. These technologies are particularly useful to address care needs in rural and remote communities, and they contribute to the cost- effective use of scarce human resources.

Strengthening data and information systems for program planning and evaluation: New opportunities are available to build on advancements in information and communications technology (ICT) to address the existing variation in data collection processes (tools and data elements) across provinces/territories. The inability to compare information on home and community care programs is linked to the variation and lack of compatibility of existing data collection information sets (i.e., common definitions, common/minimum data sets, classification systems, client assessment instruments, indicators).

Setting Priorities: Strategies for Collaboration

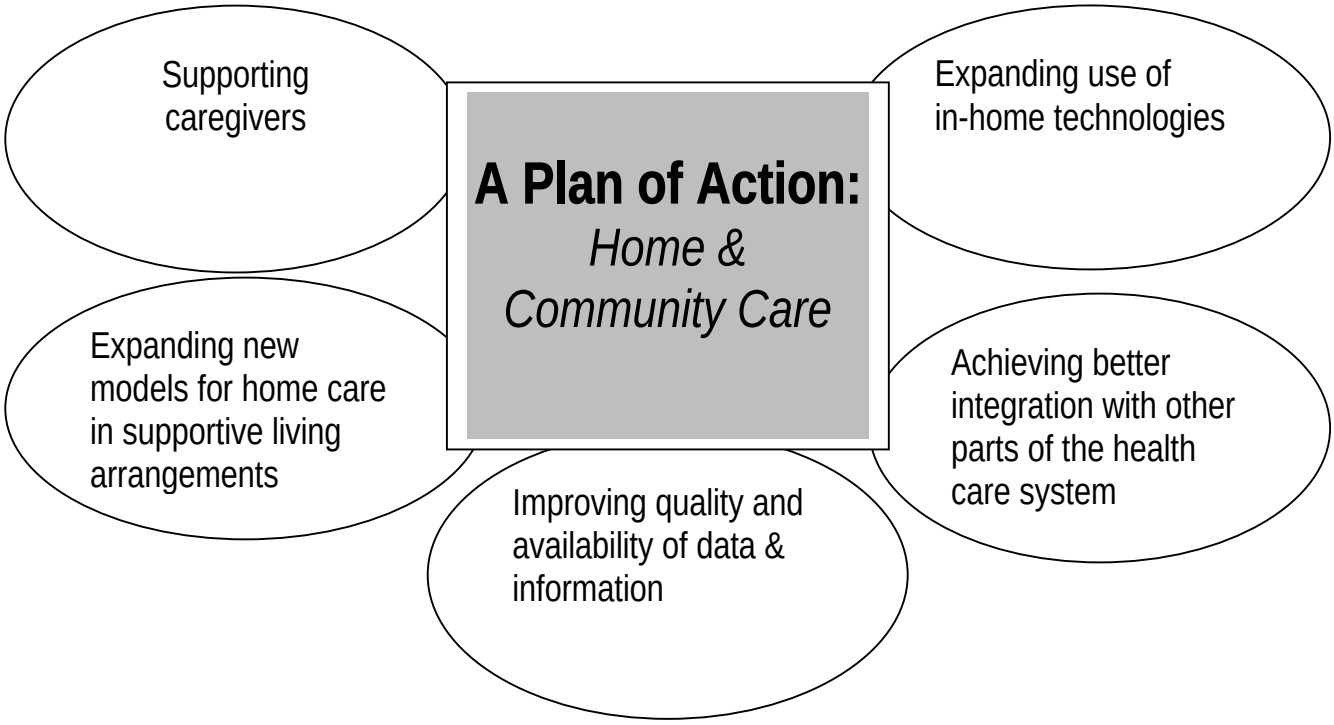
The strategies included in the plan of action represent areas where there is both strong agreement and support that provincial/territorial collaboration will help to respond to the key drivers of change in the home and community care sector. The additional criteria that were used to identify the strategies are outlined below.

Criteria	*Description*
Importance and relevance	- Importance of the issue to the home and community care agenda - Relevance of the issue in promoting the concept of a continuum of health care across care sectors and throughout client/patient life phases
Potential to improve accessibility to home and community care services appropriate to the needs of the client	- Opportunities for home and community care to improve service delivery options for the client - Opportunities for home and community care to address the pressure points on the health care systems
Potential to achieve collaboration and cooperation among provinces/territories	- Provincial/territorial desire in advancing work in the area to improve access to and quality of services for the client - Potential of the issue to generate buy-in, collaboration and support across provinces/territories - Potential of initiative(s) to be implemented across provinces/territories where appropriate - Potential to identify areas of common interest to provinces/territories
Ability to build on best practices and expand on demonstration projects	- Ability to advance and/or capitalize on lessons learned from 'best practice' initiatives - Potential to support and/or advance opportunities in the current reform environment
Ability to contribute to sustainability of the health systems	- Ability to evaluate and provide evidence on effectiveness - Potential to enhance mechanisms for public accountability on home and community care performance - Ability to measure cost/benefit and efficiency to make systems more sustainable
Application and potential to address services in rural and remote areas	- Potential to impact on and/or address gaps and barriers in delivering home/continuing care services in rural, northern and remote communities
Potential to attract necessary support for the issue	- Potential to generate public, stakeholder and government support for the issue

Based on these criteria, there was consensus among provinces/territories that a plan of action be developed to advance work related to each of the following strategies:

STRATEGIES TO STRENGTHEN PROVINCIAL/TERRITORIAL HOME AND COMMUNITY CARE PROGRAMS	
Strategy 1	Supporting caregivers
Strategy 2	Expanding use of in-home technologies to improve home and community care delivery to benefit clients, caregivers, and providers
Strategy 3	Expanding new models for home care in supportive living arrangements
Strategy 4	Achieving better integration between home and community care and other parts of the health care system
Strategy 5	Improving quality and availability of information on home and community care services

The next section of this report discusses each of these strategies in further detail. Each begins with a brief statement of the issue and a rationale describing its importance. These descriptions are followed by a proposed course of action (i.e., recommendation) for responding to the issue. The recommendations include references to the kinds of initiatives that will build on selected experiences of provinces/territories. The examples reflect what is known and likely to make a difference within the home and community care sector.



Part 2: Delivering on the Plan of Action

Strategy 1: Supporting caregivers[30]

Statement of Issue

Caregivers[31] play a significant role in enabling people to remain in the community, avoid premature admission to long-term care facilities, and allow earlier discharge from hospital. It is estimated that caregivers provide 75 to 90 per cent of care in the home.[32] Today, increased pressures are being placed on caregivers in response to an overall shift to caring for clients in the community as part of the modernizing and restructuring of health care systems across the country. Currently, direct government support for caregivers is limited.

Rationale

- Home and community care is based on a client-centered approach to care. Its success is strongly dependent upon the active participation of family caregivers who currently provide, on average, 28 hours of care per week in the home.[33]

- In 1996, 2.6 million Canadians (12 percent of the population) reported providing unpaid assistance to someone with long-term health problems.[34] The significant shift in responsibility to family caregivers has occurred at a time when other changes are straining the family's capacity to cope with increased responsibility for home and community care (e.g., changing family patterns, lower fertility rates, increased labour force participation by women, mobility and migration patterns). There is also growing evidence of multiple caregiving experiences; a phenomenon that may accentuate as the supply of caregivers decreases.[35]

- Lack of adequate respite services was the single most frequently cited service gap for children with special needs in a recent study of home and community care. While respite may be available, it was perceived as insufficient to meet the needs of these

[30] The Ministers Responsible for Seniors have identified the issue of caregivers as a priority and discussed a number of strategic directions at their meeting in June 2002.
[31] This includes family and friends.
[32] *Canadian Home Care Human Resources Study. Phase 1 Highlights – Setting the Stage: What Shapes the HomeCare Labour Market*. December 4, 2001. See www.homecarestudy.ca
[33] CARP. *Putting a Face on Home care*. 1999. See www.50plus.com
[34] Cranswick, K (1997) *Canada's Caregivers*. Canadian Social Trends Backgrounder, Winter, 1997, Statistics Canada, Catalog no. 11-008-XPE. http://www.hc.sc.gc.ca/seniors-aires/pubs/unsorted/survey.htm.
[35] Ibid.

families.[36] The expected demand for respite care is four times the current reported use, and for elder care and palliative care the expected demand is about three times the level of current use.[37]

- In several provinces/territories, the increasing complexity of home and community care is requiring caregivers to assume varied, specialized and complex tasks traditionally assumed by health and social service professionals. This trend has highlighted the need for adequate training of caregivers to ensure that they are able to meet the medical and personal care needs of those cared for in the home.

- Most caregivers are women. It is estimated that one half of women aged 35 to 64 can expect to care for a dependent parent. As they are called upon to provide more stressful and intensely personal care, more than twice as many female as male caregivers felt that their caregiving was affecting their health. They report high stress levels, fatigue, negative emotions, depression, psychological distress, interpersonal conflict, loss of sleep and social isolation.[38]

Recommendation

Explore options that will provide support and assistance to family and other caregivers who care for people in the home. Options could include flexible work arrangements, elder care leave, respite care, and training and education required to support caregivers in their role.

[36] Hollander M.J. and Prince, M.J., (February 2002). *"The Third Way": A Framework for Organizing Health related Services for Individuals with Ongoing Care Needs and Their Families.*
[37] *The Berger Monitor*, 1999
[38] Ontario Community Support Association (February 2001). *In 20 short years – a discussion paper on demographics and aging.*

Toward "best practices" in caregiver support

Sharing experiences and/or collaborating at the provincial/ territorial level to:

- ***Develop information materials and training/education programs to assist caregivers in their roles***. These programs focus on providing caregivers with information and training/education to support them in their roles. Information is aimed at helping caregivers care for family members at home including guidance on exercising choices in treatment, maintaining patient autonomy, and avoiding caregiver burnout. Programs can be made available either directly or by providing funding and/or staff support for educational and individual caregiver supports. Information/ education can be accessed through a variety of modalities, including: caregiver coalitions/support networks, telephone support services, print materials and/or web-based information on a variety of topics (e.g., chronic diseases, accessing respite and other community services, caregiver support networks).

- ***Offer a wide variety of respite programs to address different needs of caregivers.*** These programs could include day centres, more flexible in-home respite services, and overnight/ extended stay respite programs in long term care facilities. Some provinces/territories are offering "day centre" respite programs that offer clients and their families access to services that includes therapeutic activities and caregiver relief 24 hours, seven days a week.

Strategy 2: Expanding use of in-home technologies

Statement of Issue

Advancements in treatment protocols, in-home monitoring devices, accessibility to high-tech equipment and communication technologies allow for the delivery of complex and sophisticated therapies and treatments in the home and community. Conditions and treatment services that previously required hospitalization such as pain control, infusion therapy, chemotherapy, dialysis, intravenous therapy and other specialized medical services can now be delivered in the home environment.

In addition, diagnostic assessment tools, patient monitoring devices, telehealth[39] and community care services are also more broadly available to support a variety of care delivered in the home setting including:

- Health supervision and education,
- Health assessment, vital sign and oxygen monitoring,
- Monitoring of chronic illness (e.g., emphysema, congestive heart failure, diabetes),
- Post-surgery monitoring and follow-up,
- Client and caregiver education and training,
- Follow up to in-person therapy to assess progress,
- Palliative care assessment,
- Visual wound assessment,
- Integrated mental health care (assessment, counseling, education),
- Assessments of home environment to provide recommendations for modifications, and
- Linkages to rural and isolated communities.

[39] **Telehealth:** Generally refers to "the use of telecommunications and information technologies to deliver health and health care and information over long and short distances": commonly understood to include three major aspects - telecare, telemedicine and e-health (Adapted from "*The Telehealth Industry in Canada*", July 1997)
Telecare: Generally refers to telephone health care triage services "provided by registered nurses, that may include assessment and referral, information and education, and self-care support" (Developed for Self-Care/Telecare Issue Paper prepared for the F/P/T Advisory Committee on Health Services)
Telemedicine: Generally refers to "The delivery of health services and the transmission of health information (through video conference and store and forward) using telecommunications for clinical and educational purposes" between 2 or more sites (including telehomecare). (Adapted from "*Fragmentation to Integration: The Telemedicine Industry in Australia"*, John Mitchell 1998)

Rationale

- The provision of complex care in the home environment through advancements in technology (e.g., tele-home care) is an adjunct to, not a substitute for, traditional home care. These programs offer a new model of service delivery, which have the potential to increase health system efficiency but may also help resolve access issues for patients where geographic distances and human resources issues make care a particular challenge.

- Advancements in the use of technology have allowed for distance education of clients and providers, and client assessments in a cost-effective manner. Use of these technologies have been demonstrated to facilitate earlier discharges from acute care facilities, to decrease use of emergency departments, to improve access to medical specialists, and to increase efficiency of nursing time during a period of human resources shortages.

- New technology requires more highly skilled staff to provide the more complex care. The ability to care for higher acuity clients in the home setting has also generated:

    - A need for more sophisticated systems and training (for both formal and informal caregivers) to ensure that procedures are safely administered in the client's home.
    - Concerns about the high costs for supplies and equipment for home care programs and for clients.

- Advancements in information and communications technology has also created new possibilities for the integration of services across settings – from hospitals to community clinics to individual homes – with clinical and administrative information shared across health care sectors.

Recommendation

Identify approaches to facilitate broader adoption of technology for use in home and community settings with a focus on expanding and enhancing:

- ***The use of medical and equipment technologies to support in home services; and***
- ***Telehealth technologies to assess, treat, and monitor clients, and provide client and caregiver training and education.***

Toward "best practices" in-home technologies

Sharing experiences and/or collaborating at the provincial/ territorial level to:

- ***Enhance provision of specialized/complex medical services in the home and community environment.*** These programs provide professional and support staff and the necessary equipment required to care for complicated health care needs and/or technologically dependent clients with complex, often life-threatening conditions, at home. In a number of provinces/territories, IV therapy, dialysis, pain pumps and chemotherapy are now available in the home setting. Additionally, to meet the unique needs of families with high needs children with serious health conditions, some provinces provide extraordinary funding to the family to help them effectively meet their child's intense and complex health care needs through home and continuing care services.

- ***Use telehealth technology to monitor, assess, support and intervene in caring for clients with a number of health conditions at home and in the community through health professional virtual visits.*** Telehealth technology can, for example, be used to monitor post-surgical patients via devices that instantaneously transmit blood pressure, oxygen saturation, and heart rate to telehealth nurses/physicians over the phone line. The technology also allows for real-time video interaction, making remote wound management and virtual patient assessments a reality. It has been used for integrated mental health care to assess, counsel and educate clients and their caregivers. Home telehealth has been shown to be an effective substitute for some face to face home care visits, is able to provide high satisfaction to clients and health providers, and maintain the quality of care to clients in a cost effective manner.

- ***Develop and/or expand telephone advice services:*** These programs improve the use of the health system by providing confidential telephone service for individuals who call to get health advice or general health information from professionals about health-related concerns 24 hours a day, 7 days a week. They have successfully been implemented in a number of provinces/territories.

Strategy 3: Expanding new models of home care in supportive living arrangements

Statement of Issue

Increasingly, jurisdictions in Canada and abroad are recognizing the benefits and efficiencies of providing innovative approaches to home and community care services to a group of individuals within alternative living arrangements. However, availability and access to these environments is limited in most provinces/territories.

In several jurisdictions an important part of enabling people to remain living in the community is the ability to provide supportive living environments that combine accommodation and support services. Supportive living arrangements can provide an option for those who have limited access to caregiver support to stay in the community. These individuals can continue to live independently with access to flexible on-site services and support within their living environment. Supportive living combines building features and support services to enable people to meet their daily needs and remain physically and emotionally secure. This alternative will provide more choice and greater flexibility for clients who want to continue residing in the community.

Rationale

- The goal of supportive living is to facilitate independent living for individuals who are unable to meet some or all of their daily needs and/or who require monitoring or access to assistance to remain physically and emotionally secure.

- It is often fear and the risk of living alone (rather than increased care needs) that compels seniors, persons with disabilities or individuals managing chronic health conditions to move to a facility-based care setting. Supportive living has been identified as a good housing and care option for these individuals as well as for persons with serious mental health problems. Supportive living environments provide an alternative for addressing the needs of all of these populations in a cost-effective manner that prevents long-term care institutionalization.

- There is a need to educate both the public and providers regarding the availability and role of supportive living environments and to communicate the benefits provided by these models, including their potential to provide opportunities for:

    - lower cost services (compared to long-term care facility costs)
    - increased consumer choice
    - increased flexibility in the delivery of care customized to client needs
    - more efficient use of home care workers' time (e.g., decreased travel)
    - more appropriate and efficient use of long-term care facility beds, and

- public-private partnerships that will enhance consumer choice and complement public programs/services.

- Supportive living models provide opportunities for public- private partnerships based on the benefits to be achieved by building on the "unbundling" of housing from home and community care services. Private or public corporations can build and maintain supportive living units (apartments, housing units) in communities where there is a need, while government continues to provide home and community care services. Such initiatives can improve access to capital and technologies, contain costs, and increase efficiencies.

Recommendation

Support collaboration between home and community care and housing providers to develop innovative and affordable supportive living and other facility arrangements. These arrangements should:

- ***Build on the successful implementation of supportive living models in a number of provinces;***
- ***Consider the benefits to be acquired through public-private partnerships; and***
- ***Include communication strategies that promote the advantages of supportive living to the public and providers.***

Toward "best practices" in supportive living arrangements

Sharing experiences and/or collaborating at the provincial/ territorial level to:

Develop a range of assisted living projects: These models include a variety of building and housing settings that can be targeted to diverse client groups (e.g., frail seniors, persons with dementia, people with disabilities, mental health clients). For example "aging in place" models offer a combination of private condominiums, apartments, assisted living spaces and nursing home beds for older clients. Services provided for each type of accommodation vary depending on client needs. Examples of supportive living arrangements currently in place in some provinces/ territories include designated assisted living, designated group homes, enhanced lodges, lodges and adult family living/family care homes. There are also "aging in place" complexes that consist of private residences, supportive living units and a long-term care facility to provide access to the continuum of care in a single location.

Strategy 4: Achieving better integration between home and community care and other parts of the health care system

Statement of Issue

In order to ensure that clients receive the right service, in the right place at the right time, stronger linkages must be achieved at both the organizational and provider level *within* and *between* health care sectors, which include home and community care, primary care, acute and long-term. The home and community care sector plays a key linking role between acute care, long-term care facilities, and primary care, yet there are still many people who know little about home care and how to access it. Stronger linkages among providers and between organizations will improve optimal service delivery for the client, enhance efficiencies, and develop a more coordinated and cohesive continuum of care.

Rationale

- A lack of communication and organization between the home and community care sector and other sectors (acute care institutions, long term care facilities, primary health care) of the care continuum is a significant barrier to effective co-ordination of patient care across hospital, community and other provider groups. There is a need to better understand how the system components "fit together" so that effective strategies can be developed to better coordinate, link and integrate the home and community care sector with other players in the system.

- As well as performing its role as a substitute for long-term care facility placement, home and community care services are increasingly being used to decrease emergency department utilization, prevent acute care hospital admissions, and facilitate earlier discharge from in-patient hospital care. Home and community care programs can also provide a single point of entry into the health care system with case managers helping clients navigate through the health system to facilitate meeting their needs in the most efficient manner.

- The relationship between home and community care and long-term care facilities is complementary. In some situations home care can delay or prevent admission to long-term care facilities. However, a certain proportion of the population will have health care requirements that are not appropriately accommodated at home. In other cases, facilities can provide extended respite to caregivers of home care clients.

- There is a need to strengthen the linkages between home and community based services with acute care and residential/facility-based services. There is also a need to determine the role of the family physician in planning and implementing home care services. In many parts of the country, the family physician has been largely excluded from home and community care planning and implementation.[40] An across Canada

[40] The College of Family Physicians of Canada. (December 2000). *The Role of the Family Physician in Home Care – A discussion paper*. P2. See http://www.cfpc.ca/communications/homecare.asp

survey of family physicians indicated that 60 per cent said they were not informed when their patients were referred to home care. [41]

Recommendation

Examine approaches that will improve the continuity of care for the client by enhancing coordination and linkages between:

- ***Home care providers;***
- ***Home care providers and other health care providers (in acute care, primary care and long-term care sectors); and***
- ***Home and community care information with other health information to improve client care.***

Toward "best practices" in achieving better integration between home and community care and other parts of the health care system

Sharing experiences and/or collaborating at the provincial/ territorial level to:

Establish 'liaison' positions between acute care facilities/emergency departments and home and community care programs: The use of home and community care liaisons/ case managers in Emergency Departments is an example of a new kind of linkage being established to bridge the gaps in the care continuum. 'Liaison' positions can support home care delivery by identifying clients in hospital that can be served by home care to facilitate discharge planning and admission to home care services. Liaison staff also provide education and information for both providers and clients (e.g., educate hospital staff, clients and families in regards to home care).

[41] The College of Family Physicians of Canada (December 2000*). The Role of the Family Physician in Home and community care – A discussion paper*. P. 6 .
See http://www.cfpc.ca/communications/homcare.asp

Strategy 5: Improving quality and availability of information on home and community care services

Statement of Issue

All provinces/territories collect information on home and community care. However, the systems among jurisdictions vary both in terms of the data gathered, the sophistication of the information generated, and the information systems utilized. Variations amongst each of the provinces/territories in the development of their databases and information systems makes it difficult to obtain various kinds and levels of data or compare data across jurisdictions. Lack of data and comparability of data also hamper the development of an evidence base to support decision-making related to home and community care.

Rationale

- Although most provinces/territories have standardized their internal systems of *client classification* and *data collection*, there are significant differences across systems. These differences make it difficult to develop provincial/ territorial comparisons across Canada about who is receiving home and community care, what and how care is being delivered, and with what outcomes.

- There is increasing recognition of the potential value of sharing information across provincial/territorial boundaries, including facilitating development of a shared knowledge base on what works best in home and community care services.

- Increased comparability of data elements would help to improve the adequacy and reliability of home and community care data and information systems and allow provinces/territories to:

  - Monitor and compare the health characteristics/status of home and community care clients and related service requirements of those who receive home and community care services;

  - Support the collection and analysis of information related to workload measurement, client-outcome measurement, service utilization and client satisfaction;

  - Improve understanding of the relevance, effectiveness, and efficiency of home and community care services within and across jurisdictions;

  - Set a strong research agenda for identifying and fostering the adoption of 'best practices' across provinces/territories about home care needs and services;

- Better understand the relationship and linkages of home and community care use with other components of the health care continuum;

- Enhance system accountability and evidence-based decision-making through the gathering and analysis of common data sets for monitoring of system-wide outcome measures and performance indicators.

Recommendation

Collaborate to identify common data elements across provinces/territories that will:

- ***Promote consistent classification of clients;***
- ***Allow for comparison of home and community care client services and outcomes;***
- ***Lead to better research and evidence-based decision-making; and***
- ***Provide for linkages with other settings/levels of care***

Toward "best practices" in improving quality and availability of information on home and community care services

Sharing experiences and/or collaborating at the provincial/ territorial level to:

Implement objective client assessment and data collection tools with common data elements: At the individual level, these tools prevent duplication of assessments, promote sharing of information between providers, and ensure an appropriate determination of client needs and the development of a service plan suited to client needs. At the system level, the data collected can be grouped to allow for comparison and analysis to inform decision-making and promote accountability.

Develop an electronic health record: This record would include client information related to screening; assessment and needs determination; care planning; clinical management; performance measures and indicators; case mix funding modeling; and technology evaluation.

The Way Forward: Next Steps

- Provinces and territories are united in their commitment to work together to meet the challenges of growing expenditures and public needs and expectations for home and continuing care services.

- In recent years, provinces/territories have invested heavily in their home and community care systems, and have undertaken considerable work to strengthen the ability of the sector to respond to growing and changing pressures in a sustainable way.

- The five strategies identified in the plan of action represent specific areas where provinces/ territories believe they can be more effective individually by working collectively.

- The extent of collaboration regarding implementation of the strategies, however, will vary depending on the strategy. For example, the recommendation calling for the identification of shared data elements across provincial/territorial information systems will require information sharing and collaboration in order to succeed. On the other hand, approaches to responding to support for caregivers or expanding new models for home care in supportive living arrangements may move further faster if implemented at an individual provincial/territorial level by building on 'best practices' in other jurisdictions.

- While innovations exist in the home and community care sector, there is a misperception that there is consensus on what constitutes best practices. This is not the case for a number of reasons:
    - Home care clients' needs have diversified and are more complex;
    - The growth of home and community care programs in the past 10 years has been exceptionally rapid; and
    - Outcome information linking client outcomes to the care delivered and the cost is limited.

- Information pertaining to all of these areas (client needs, home care programs, and outcome data) is necessary to identify strengths and weaknesses of home and community care programs and to discover and disseminate best practices in this area.

- The next steps required to further the plan of action are for provinces/territories to:

    - Determine individual priorities for each strategy based on the needs and characteristics of their jurisdiction.

    - Share information and collaborate to move strategies forward.

- Leverage the strengths of the projects and experiences of provinces/territories to identify best practices in each of the strategic areas (i.e., targeted identification of things working well that other jurisdictions could build on/benefit from).

- Determine what constitutes 'best practices' related to each strategy.

- Identify specific initiatives that will advance (both individually and collaboratively) each of the strategies by each jurisdiction.

- Collaborate to identify priorities for future research to identify and build on international best practices in home and continuing care over the long term.

Concluding Remarks

Home and community care services have become an integral and growing component of the health care systems in Canada. Expansion in this sector and the growing demands being placed on it, symbolize the 'modernization' of health care systems unfolding across the country. The characteristics of a mature and effective home and community care sector are that it is accessible, facilitates continuity of care across the health system, provides care that is evidence based for positive health outcomes (prevention and care), and that it provides value for money.

This report calls for a strengthened focus on home and community care. It builds on the belief that there is strong potential in provinces/ territories to collaborate around common strategies and build upon existing capacity and experiences to avoid duplication between jurisdictions and work toward identification of 'best practices'.

Provincial/territorial collaboration around the specific strategies identified in this report would go a long way to developing and sharing best practice information about what types of innovation work (and which don't). Partnerships among the provinces/territories to advance work in these areas would also help develop strategic communication initiatives and collaborative research agendas that will yield new information and set priorities for future planning within the sector.

Building a more sustainable health care system will require greater sharing of information and collaboration among provinces/territories. There is also a hope that shared commitment and collaboration among provinces/territories will compel the federal commitment to support needed growth and change in this sector.

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