

Home Care in Canada: From the Margins to the Mainstream

Les soins à domicile au Canada : de l'exclusion à l'intégration



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Health policy is a political sector that, more than others, absorbs and reflects national developments, traditions, and cultures. Health systems are the results of decades of development and the rather individual response to a country's social situation and profile.

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Executive Summary

Home care is a key part of our health care system that has the potential to affect all Canadians. At some point in their lives, many Canadians will find themselves on either the giving or the receiving end of home care. It is a pan-Canadian challenge that requires attention, as care is increasingly being provided in the home.

Four main reasons are behind this shift:

- People generally prefer to receive care at home.
- Canada is an aging nation with increasing rates of chronic disease.
- Current technology allows us to offer more care at home.
- Governments are trying to contain their health care budgets, and home care is generally perceived to be lower-cost care.

Those who may need home care include individuals requiring continuing care after being discharged from hospital; persons who are dying; persons with a mental illness; frail elderly people who wish to remain in their home; persons with physical or mental disabilities able to live independently; children with special needs; and people with chronic disease(s). This list underscores the broad scope of home care and its importance to the health system.

Home care can permit individuals to live at home with independence and dignity, and is part of the solution to some of the challenges facing our health system, such as lengthy wait times for placements and procedures, pressures on emergency departments, inappropriate use of hospital beds, and a shortage of long-term care beds.

Home care involves a wide range of services and a wide range of caregivers: health professionals, paid caregivers and volunteers. These



volunteers include family members, friends, neighbours or members of community organizations. In fact, home care could not exist as we know it without the large body of volunteers who support it.

Home care is not an insured service under the *Canada Health Act*. Unlike services currently defined as medically necessary (hospital and physician services) that receive public funding (termed “first-dollar coverage”), home care is an “extended” service, and hence there is no obligation on the part of governments to provide a minimum basket of services.

Funding home care services is challenging for two reasons. The first is location. Home care involves both medical and social care in a home or community setting. When the location of care moves out of the hospital, non-physician services that would have been covered in the hospital no longer need to be — even though they may be deemed “medically necessary.” The *Canada Health Act* defines these services in terms of who delivers them (primarily physicians) and where the services are delivered (hospitals). This traditional view of health delivery becomes problematic, as care is delivered in varied locations.

The second reason is that home care encompasses both social and medical services. Home care clients obtain such care for three reasons: acute care substitution, long-term care substitution, and prevention and maintenance. Home care includes care that is not “medical,” although it can be valuable — and even essential. This raises the question of which services should or should not be publicly covered.

This ambiguity around home care in turn fosters lack of clarity as to who should receive publicly funded home care services, and which services they should receive.

Variations exist across the country in the type and volume of services provided, cyclical funding and underfunding, and differences in service delivery models.

In 2004, federal, provincial and territorial governments agreed on first-dollar coverage for home care services in three areas. Under the 10-Year Plan to Strengthen Health Care (2004 Accord), they agreed to publicly fund:

- two weeks of short-term acute home care after discharge from hospital;
- two weeks of short-term acute community mental health home care; and
- end-of-life care.

Apart from these three areas, differences exist not only *among* provinces and territories but also *within* them. There is variability in access to and provision of home care services and differences in the use of and application of co-payments and user fees. The delivery of appropriate home care services will continue to be a challenge until policy-makers realize its importance to the changing health system and focus on making services more equitable across the country.

Home Care in Canada: From the Margins to the Mainstream:

- explores the home care landscape in Canada with the purpose of broadening awareness, stimulating debate and promoting action;
- identifies gaps and opportunities with respect to groups of people whose home care needs are not being adequately addressed (3–4 percent of seniors, those who need long-term home care, children, dying persons, First Nations and Inuit, and people with mental illness); equitable services; co-payments and income testing; services not offered through home care; drugs, supplies

and equipment; limits to care provision; information technology, electronic health records and telehealth; and case management;

- highlights the experience of Australia, a country chosen because it is similar to Canada in size, parliamentary government, widely dispersed population, and its Aboriginal population. Australia established a national home care system and has honed it over two decades. In moving forward on home care policy, Canada can look to Australia as a role model;
- focuses on caregivers, 80 percent of whom are informal or unpaid. In 2007, nearly one in four Canadians reported caring for a family or friend with a serious health problem in the previous year. Many have taken leave from work or have left jobs, often with serious repercussions for their personal health and finances and the economic health of the country;
- reviews the availability of tax credits and the Compassionate Care Benefit with an eye to those informal caregivers who fall outside its parameters;
- examines how some other countries are choosing to recognize and support their informal caregivers;
- explores the challenges of recruiting and retaining the home care workforce, and how they can be mitigated;
- synthesizes the large body of research on the various forms of home care in Canada, particularly over the past decade, exploring what we have learned about the efficacy and cost-effectiveness of both long- and short-term home care; and
- brings the reader up to date on funding options.

Finally, this brief offers recommendations to all governments and stakeholders to address the challenges Canada faces:

1. Ensure integration and expansion of home care within the continuum of care.
 - 1.1 Expand, improve and identify standards for home care to ensure equitable access and to include long-term maintenance and prevention services.
2. Ensure predictable and sustainable funding in home care.
 - 2.1 Address the issue of co-payments and user fees.
 - 2.2 Expand pharmacare to those receiving home care.
 - 2.3 Reduce inequities among and within provinces and territories.
 - 2.4 Consider having the funding follow the client to allow for portability.
3. Introduce appropriate and relevant pan-Canadian principles to address a greater integration of home/community care.
 - 3.1 Define and expand the basket of services.
 - 3.2 Introduce a separate piece of legislation with appropriate and relevant principles to address a greater integration of home, community and long-term care on a pan-Canadian basis.
 - 3.3 Establish minimum standards and accountability mechanisms.
 - 3.4 Establish strong federal leadership.
4. Provide appropriate supports to both formal and informal (usually family) caregivers.
 - 4.1 Minimize the financial burden placed on informal caregivers through means such as amending the Canada Pension Plan/Quebec Pension Plan.

- 4.2 Provide additional supports for caregivers.
- 4.3 Increase the flexibility and availability of respite care.
- 5. Address the public/private split in terms of access to and quality of services, as well as transparency and accountability.
- 6. Invest in health human resources.
 - 6.1 Promote, encourage and strengthen home care health human resources through:
 - targeted recruitment and retention, and
 - education and training opportunities.
- 7. Make greater use of information and communications technology.
- 8. Share leading practices and experiences from both within and outside Canada.

Home care is moving from the margins to the mainstream of our health system. Given Canada's evolving demographics, social realities and changing care patterns, home care will assume greater importance. This is the new landscape for policy-makers. With this brief, the Canadian Healthcare Association, whose members span the country and the health continuum, urges governments to give the home care sector and its caregivers the long-overdue policy recognition they deserve.

Sommaire

Sommaire

Les soins à domicile sont un volet important de notre système de santé et sont susceptibles de toucher tous les Canadiens. À un certain moment de leur vie, bien des Canadiens figureront parmi ceux qui offrent ou ceux qui reçoivent des soins à domicile. La question est de nature pancanadienne et il faut y porter attention, car les soins à domicile connaissent une croissance constante.

Quatre raisons principales justifient une telle attention :

- les gens préfèrent généralement recevoir les soins à domicile;
- la population canadienne est vieillissante et les taux de maladies chroniques sont à la hausse;
- la technologie actuelle nous permet d'offrir plus de soins à domicile;
- les gouvernements s'efforcent de contenir les budgets de la santé et les soins à domicile sont généralement considérés comme moins coûteux.

Parmi les personnes qui peuvent avoir besoin de soins à domicile, on compte les personnes qui ont besoin de soins continus après une hospitalisation; les personnes en fin de vie; les personnes atteintes de maladie mentale; les personnes âgées fragiles qui désirent rester dans leur domicile; les personnes atteintes d'incapacités physiques ou mentales, mais capables de vivre de façon autonome; les enfants ayant des besoins spéciaux; et les personnes atteintes de maladie(s) chronique(s). Cette liste souligne la vaste étendue des soins à domicile et leur importance dans le système de santé.

Les soins à domicile peuvent permettre à des personnes de vivre à la maison avec autonomie et dignité et font partie de la solution pour relever certains défis auxquels notre système de santé est confronté, tels les longs temps d'attente pour obtenir des services ou une place en établissement,



les pressions sur les services d'urgence des hôpitaux, l'utilisation inadéquate des lits d'hôpitaux et la pénurie de lits de soins de longue durée.

Les soins à domicile comportent une vaste gamme de services et font intervenir de multiples soignants : des professionnels de la santé, des intervenants rémunérés et des bénévoles. Ces bénévoles sont des membres de la famille, des amis, des voisins ou des membres d'organisations communautaires. En fait, les soins à domicile ne pourraient exister sous leur forme actuelle sans le grand nombre de bénévoles qui les soutiennent.

Les soins à domicile ne font pas partie des services de santé assurés en vertu de la *Loi canadienne sur la santé*. Contrairement aux services actuellement définis comme étant médicalement nécessaires (les services hospitaliers et les services médicaux) qui sont subventionnés par des fonds publics (couverts à partir du premier dollar), les soins à domicile sont des soins « complémentaires » et de ce fait, les gouvernements ne sont pas tenus d'offrir une gamme minimale de services.

Le financement des services de soins à domicile est problématique pour deux raisons. La première a trait au lieu. Les soins à domicile comportent des soins médicaux et des soins sociaux prodigués dans une maison ou dans un milieu communautaire. Quand les soins doivent être prodigués dans un nouveau milieu après une hospitalisation, il n'y a plus d'obligation légale d'offrir les services offerts par des personnes autres que des médecins qui auraient été couverts en milieu hospitalier, même s'ils sont jugés « médicalement nécessaires ». La *Loi canadienne sur la santé* définit ces services en fonction de la personne qui les offre (généralement un médecin) et du lieu de la prestation (généralement un hôpital). Cette conception traditionnelle de la prestation des soins devient problématique, car les soins sont offerts dans divers milieux.

La deuxième raison est liée à la nature des soins à domicile qui comprennent à la fois des services sociaux et des services médicaux. Les clients des soins à domicile les reçoivent pour trois raisons : le remplacement de soins de courte durée, le remplacement de soins de longue durée et la prévention et l'entretien. Les soins à domicile comprennent des soins qui ne sont pas « médicaux », même s'ils sont précieux et parfois même essentiels. Cela soulève donc la question de savoir quels services devraient être couverts par les fonds publics et quels services ne devraient pas l'être.

Cette ambiguïté relative aux soins à domicile fait également ressortir une certaine confusion par rapport aux personnes qui devraient recevoir des services de soins à domicile subventionnés par le secteur public et la nature des services qu'elles devraient recevoir. Il existe de grandes variations dans le pays par rapport au type et au volume des services fournis, au financement cyclique et au sous-financement, ainsi qu'aux modèles de prestation.

En 2004, les gouvernements fédéral, provinciaux et territoriaux se sont entendus pour couvrir dès le premier dollar les services de soins à domicile dans trois domaines précis. En vertu du Plan décennal pour consolider les soins de santé (Accord de 2004), ils ont convenu de financer par des deniers publics :

- des soins actifs à domicile de courte durée pendant deux semaines après le congé de l'hôpital;
- des soins actifs communautaires de santé mentale pendant deux semaines;
- des soins de fin de vie.

À part ces trois domaines, il existe des différences non seulement entre les provinces et les territoires, mais également au sein d'entre eux. L'accès aux soins et la

prestation des services varient d'une autorité à l'autre, tout comme les règles relatives à la participation au coût et aux tickets modérateurs. La prestation de services de santé à domicile appropriés continuera de poser problème tant que les décideurs n'auront pas réalisé son importance par rapport à l'évolution du système de santé et n'accorderont pas une plus grande attention à la prestation de services plus équitables à la grandeur du pays.

Le mémoire Les soins à domicile au Canada : de l'exclusion à l'intégration :

- examine la situation des soins à domicile au Canada dans le but de sensibiliser l'opinion, de stimuler le débat et de promouvoir l'action;
- identifie les lacunes et les possibilités en ce qui a trait : aux groupes de personnes dont les besoins en soins à domicile ne sont pas satisfaits (de trois à quatre pour cent des personnes âgées, les personnes qui ont besoin de soins à domicile de longue durée, les enfants, les personnes en fin de vie, les membres des Premières nations et les Inuits, les personnes atteintes de maladie mentale); aux services équitables; à la participation aux coûts et à la prise en compte des revenus; aux services non offerts à domicile; aux médicaments, fournitures et équipements; aux limites à la prestation des soins; aux technologies de l'information, aux dossiers de santé électroniques et la télésanté; et à la gestion des cas;
- souligne les faits saillants de l'expérience de l'Australie en ce domaine, un pays choisi pour ses similarités avec le Canada sur le plan de la taille, du système parlementaire, de la répartition de sa population sur un vaste territoire et de sa population autochtone. L'Australie a mis

en place un système national de soins à domicile et l'a perfectionné au cours des vingt dernières années. Si le Canada allait de l'avant avec une politique de soins à domicile, l'Australie pourrait servir d'exemple;

- met l'accent sur les intervenants, dont 80 pour cent sont des aidants naturels ou des intervenants non rémunérés. En 2007, près d'un Canadien sur quatre a déclaré s'être occupé d'un parent ou d'un ami ayant d'importants problèmes de santé au cours de l'année antérieure. Plusieurs d'entre eux ont quitté temporairement ou définitivement leur emploi, ce qui a eu des conséquences sérieuses sur leur santé et leurs finances personnelles et sur la santé économique du pays;
- examine la disponibilité des crédits d'impôt et des prestations de compassion en ayant à l'esprit ces aidants naturels qui ne peuvent s'en prévaloir parce qu'ils ne répondent pas aux critères établis;
- examine comment d'autres pays décident de reconnaître et de soutenir leurs aidants naturels;
- examine les défis liés au recrutement et au maintien en poste de la main-d'œuvre des soins à domicile et cherche comment les atténuer;
- résume l'important corpus de recherche sur les diverses formes de soins à domicile au Canada, particulièrement au cours de la dernière décennie et examine ce que nous avons appris sur l'efficacité et la rentabilité des soins à domicile de courte et de longue durée;
- informe le lecteur des diverses options de financement.

Finalement, ce mémoire présente à tous les gouvernements et aux parties intéressées des recommandations visant à relever les défis auxquels le Canada est confronté :

1. Assurer l'intégration et l'expansion des soins à domicile dans le continuum de soins.
 - 1.1 Étendre et améliorer les soins à domicile et établir des normes pour assurer l'accès équitable et inclure des services de maintien de longue durée et de prévention.
 2. Assurer le financement prévisible et durable des soins à domicile.
 - 2.1 Examiner la question de la participation aux coûts et des tickets modérateurs.
 - 2.2 Étendre l'assurance-médicaments à ceux qui reçoivent des soins à domicile.
 - 2.3 Réduire les iniquités au sein des provinces et territoires et entre ceux-ci.
 - 2.4 Envisager des mécanismes faisant en sorte que le financement suive le client pour favoriser la transférabilité.
 3. Adopter des principes pancanadiens appropriés et pertinents pour mieux intégrer les soins à domicile et les soins communautaires.
 - 3.1 Définir et étendre la gamme de services.
 - 3.2 Adopter une loi distincte qui établit les principes appropriés et pertinents pour mieux intégrer les soins à domicile, communautaires et de longue durée sur une base pancanadienne.
 - 3.3 Établir des normes minimales et des mécanismes de reddition de compte.
 - 3.4 Établir un leadership fédéral solide.
 4. Offrir les soutiens appropriés aux intervenants professionnels et aux aidants naturels (généralement des membres de la famille).
 - 4.1 Réduire le fardeau financier imposé aux aidants naturels par diverses mesures, comme des modifications au Régime de pensions du Canada et au Régime des rentes du Québec.
 - 4.2 Offrir un soutien additionnel aux aidants naturels.
 - 4.3 Améliorer la flexibilité et la disponibilité des soins de relève.
 5. Examiner la question du partage public/privé en matière d'accès aux services, de qualité des services, de transparence et de reddition de comptes.
 6. Investir dans les ressources humaines en santé.
 - 6.1 Promouvoir, encourager et renforcer les ressources humaines en santé des soins à domicile par :
 - le recrutement et le maintien en poste de personnel ciblé
 - les possibilités d'éducation et de formation.
 7. Utiliser davantage les technologies de l'information et des communications.
 8. Partager les pratiques exemplaires et les expériences du Canada et d'ailleurs.
- Les soins à domicile ne sont plus marginaux, ils deviennent un courant dominant dans notre système de santé. Dans un contexte où la démographie, les réalités sociales et les modes de prestation des soins évoluent considérablement, les soins à domicile sont appelés à prendre une importance de plus en plus grande au Canada. Il s'agit de la nouvelle réalité qui se présente aux responsables des orientations politiques. Par ce mémoire, l'Association canadienne des soins de santé, dont les membres proviennent de partout au pays et de tout le continuum de soins, presse les gouvernements d'accorder au secteur des soins à domicile et à ses intervenants la reconnaissance dans les politiques qu'ils méritent depuis fort longtemps.

... there are few more important challenges than the way society treats older people. The realities of demographic change, the expectations of the 'baby boomers' and the values of a progressive centre-left government are all reasons why this issue must move from the margins to the mainstream of the government and public policy debate.

— Ivan Lewis, United Kingdom Parliamentary Under Secretary of State for Care Services¹

Introduction

Home care encompasses all aspects of the health system and involves many different players, including health professionals and their employers, unregulated health care workers, not-for-profit and for-profit organizations, volunteers and family members. There are many challenges facing home care, including the increasing demand for services coupled with broad and diverse geography and location of service delivery.

The five principles of the 1984 *Canada Health Act* — universality, public administration, comprehensiveness, portability and accessibility — outline the conditions under which the federal government will fund health services. The principles apply only to insured health services that cover hospital care (acute, rehabilitation and chronic) and medical services. They do not apply to other services, including outpatient rehabilitation care.

Home care remains an uninsured service under the Act, listed only as an extended service to which the five principles do not apply. It therefore has no protection under the Act. Provinces and territories have implemented standards to address quality and type of service. Although governments are obliged to provide some services through public funds, there are no uniform standards to ensure the quantity or type of services to be provided. There is inconsistency across the country in terms of eligibility for home care, public coverage of services, residency requirements, and access to services. There is also variability in wait times for services and service delivery. As home care is not included in the *Canada Health Act*, government policy and funding for home care may be driven by political decisions— not necessarily by public need.

Changes have taken place in health care over the years. Increasingly, patient care is shifting from the hospital to the community, and this trend will



intensify with the assistance of technology and pharmaceuticals. In the final report of the Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians — The Federal Role*, Senator Michael Kirby stated, “Canadians believe they have a healthcare system, a national healthcare system, and they don’t. They have a national hospital and doctor system, which is now 46% of the total healthcare bill and falling.”^{2 3}

In general, health care is dually funded. Health services provided by medical professionals are usually funded by the public health insurance plan. Other health professionals are publicly funded to varying degrees. However, home support services such as personal care and homemaking services are a mix of both public and private pay (out of pocket and private insurance). Fees for home support services, if publicly delivered, may or may not be means-tested and may apply to medical supplies, equipment and care. Some provinces apply a means test for home support services, while others have established a threshold for services covered. Beyond that threshold, clients must pay for the services they receive, though they may obtain some tax relief in return.⁴ (See the section “Home Care Differences Across the Country.”)

Are these home care arrangements what Canadians need? In attempting to answer this question, we must pose others.

- Is home care a medical or social need?
- At what point does home care, particularly home support services, become necessary?
- Under what circumstances should home care be paid for publicly or privately?
- When is it cost-effective and care-effective? How do we reconcile costs, autonomy, quality of care and patient safety?
- Are there conditions under which patient outcomes are compromised?
- Should those who receive this care pay co-payments, and if so, according to what criteria?
- Should a social analysis for determining fees (if utilized locally) be standardized across the country?
- Is Canada too reliant on informal caregivers to provide home care?
- Should informal caregivers, both willing and conscripted, be compensated, and if so, to what extent?
- What other supports for informal caregivers are required?
- How can equitable access to home care services be ensured across the country?

Our knowledge of home care has increased as a result of research in the field, including the 45 projects undertaken through the *Health Transition Fund* (1999–2003), and others through its successor, the *Primary Health Care Transition Fund* (2000–2006). Today, we have a better idea of home care’s promise, its limits and its many challenges than we did a decade ago.

Examining current knowledge and goals and aspirations for the future, this paper:

- defines home care;
- briefly touches on the reasons behind its emergence and growing attention from government;
- identifies challenges and opportunities;
- contrasts elements of Canada’s approach to home care to that of Australia and other nations;
- explores the evidence regarding its ability to provide good health outcomes while emphasizing that policy-makers and health professionals must focus on ensuring the integration of home care into the health system as part of the continuum of care;
- focuses on home care providers, giving consideration to several factors,

including the number of volunteers and professionals involved, gender balance, training, compensation, case management, public versus private delivery of home care services, patient and provider safety, and working conditions;

- examines the funding — and unintended or invisible costs — of home care;
- describes differences across the country, both among and within provinces and territories, in terms of access, available services and charges; and finally
- presents recommendations.

Text boxes highlight leading trends and practices within Canada and internationally, as well as lessons learned.

This brief raises questions we have not yet addressed as a nation, but must confront. At the very root of these questions lies what University of Toronto professor of health policy Raisa Deber calls “the unresolved tension as to which costs should be borne by individuals and their families, charities and society as a whole.”⁵

If we assume that the definition of health encompasses both medical and social elements, then the scope of insured home care services under Medicare should be expanded to incorporate a broader array of services. There is a lack of awareness, however, of what home care is and can be, which makes a public debate about its future challenging.

— Malcolm Anderson and Karen Parent⁶

Various Definitions

Various Definitions of Home Care

Over the years, the definition of home care has evolved.

Health and Welfare Canada, in 1990, defined home care in terms of its three key functions:

- *acute care substitution*, where home care meets the needs of people who would otherwise have to remain in, or enter, acute care facilities;
- *long-term care substitution*, where home care meets the needs of people who would otherwise require institutionalization; and
- *maintenance and prevention*, whereby people with health and/or functional deficits can remain in the home setting, both maintaining their ability to live independently and, in many cases, preventing health and functional breakdowns, and eventually institutionalization.⁷



In 2001, the Canadian Institute for Health Information (CIHI) created the *Home Care Reporting System* to provide comparable data on publicly funded home care to support policy-makers, health planners and front-line providers. The national indicators developed provide data on home care for client and system comparisons as well as information on population access, outcomes and use of resources. In doing so, CIHI developed the following definition: “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 or acute care alternatives. These services may be provided by a number of different agencies or individuals.”⁸

The Canadian Home Care Association (CHCA) developed a more inclusive definition of home care in 2004. Since then, there has been wide-scale provincial and territorial acceptance of home care “as an array of services, provided in the home and community setting, that encompass

health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family) caregiver.”⁹

The CHCA notes that home care services are for “infants, children and adults,” and often integrate “the delivery of health care services in the home setting with community services (e.g. meals on wheels, day programs, respite care facilities, volunteer services, transportation services).”¹⁰

This expanded definition highlights the broad spectrum of services that fall under home care. The increasingly widespread adoption of this definition indicates that governments and other organizations are beginning to recognize home care as a vital component in the continuum of care.

Evelyn Shapiro, the leading force behind home care in Manitoba, notes that “home care is a front-line but not a primary health service, and it is a unique blend of health and non-medical support services.”¹¹

Home care differs according to the needs of the individual. It includes medically oriented services, home support services, attendant care and preventive care, all of which enable individuals to stay in their own home. It is generally a care option for acute or post-acute patients; palliative patients; persons living with chronic conditions; frail elderly persons; those suffering from mental illness; and persons of all ages with disabilities and special needs. Home care includes such services as adult day support, assessment and case management, physiotherapy and occupational therapy, congregate living residences, equipment and supplies, group homes, nursing, home maintenance and repair, homemaker services, meal programs, palliative care, quick response teams, respite services and transportation services.¹²

Home care is often, and most appropriately, called “home and community care,” as it is not always delivered in the home. In this brief, home care is defined as ***the full array of services offered at home and in the community to support those who need help to remain in the home and those who care for them.***

... the shift from hospital to home and community is fundamentally reshaping Canadian health care policy and politics — both the way in which health care services are funded and delivered and the dynamics of health care policy making. ... home and community care are more volatile politically and more open to the logic of commercial private markets. Thus, although Medicare remains resilient, it covers a declining proportion of health care, and the role of the state accordingly diminishes.

— Patricia M. Baranek, Raisa B. Deber, A. Paul Williams¹³

Landscape in Canada

The Home Care Landscape in Canada

Funding of health care is the responsibility of the provincial and territorial governments, with a few exceptions: funding for services defined in the 2004 Health Accord and for services to populations mandated in federal legislation (the military, veterans, prisoners, First Nations and Inuit). Although some federal funding is earmarked for home care through extended service allocations, the provinces and territories are primarily responsible for the delivery of home care services.

History

1970

- Ontario formally established publicly funded home care services.

1972

- Quebec followed with the establishment of the Local Community Service Centres (CLSCs),¹⁴ bringing full home care coverage to the province by 1988.¹⁵

1974

- Manitoba became the first province to introduce a province-wide coordinated continuing care program, which was developed in response to recommendations suggesting a need for alternatives to expensive hospital care. Its *Home Care Program* provides services to all age groups.¹⁶

1975

- Newfoundland and Labrador introduced home care on a limited basis.¹⁷



1978

- *British Columbia* introduced its *Long-Term Care Program* as a province-wide initiative.
- *Alberta* established home care programs through 27 Health Units, providing professional services only to those over the age of 65. In 1984, the programs were expanded to include support services and palliative care.¹⁸
- *Saskatchewan* introduced its comprehensive program of home care and placed it under the Department of Social Services, transferring it to the Department of Health in 1983.¹⁹
- The *Northwest Territories* implemented a home care program in Yellowknife, which was expanded to include communities throughout the region.²⁰

1979

- *New Brunswick* created its Extra-Mural Hospital with a broad mandate to provide an alternative to hospital or other long-term care facilities.²¹

1982

- *Ontario* began to formally fund home support services (although Ontario first offered an acute home care program as a demonstration project in 1958).

1983

- *British Columbia* added home care nursing and community rehabilitation to its *Long-Term Care Program*, and changed the name to *Continuing Care*.

1986

- *Prince Edward Island* started its *Home Care Support Program*.²²

1988

- *Nova Scotia* began its *Coordinated Home Care Program* for those aged 65+ with limited income or long-term disabilities. A Home Care Coordinating Agency was created to deliver the program for Nova Scotia's senior citizens, disabled persons and families at risk.²³
- *Yukon* implemented its *Home Care Program* due to popular demand and strong lobbying, and the program has continued to grow.²⁴

2003

- *Nunavut*, which became Canada's newest territory in 1999, developed its own standards, policies and procedures for home care.²⁵

Models

Provincial and territorial governments have considerable latitude in choosing the basket of home care services they wish to provide, applying user fees and/or co-payments and developing their service delivery models. In 2002, federal, provincial and territorial leaders tried to define a uniform basket of services. Despite much work, no agreement was reached due to system capacity and financial limitations.

Four basic models of service delivery have evolved.²⁶

- 1) Saskatchewan, Manitoba, Nunavut, the Northwest Territories, Quebec and Prince Edward Island have a public provider model, in which provincial or territorial government employees manage and deliver both home care (which includes professional services such as nursing care) and home support services (which

include such services related to personal care, housework, meals, shopping and respite care) directly; intermediate agencies either play a limited role or have no role at all.

- 2) In British Columbia, New Brunswick and Newfoundland and Labrador, all professional services are delivered by public employees, but home support services are delivered by private agencies.
- 3) In Alberta and Nova Scotia, both public and private employees provide professional home care services; public employees provide the administration; and home support services are contracted out.
- 4) In Ontario, Community Care Access Centre (CCAC) employees provide single-entry coordinating services, but all publicly paid professional home care and home support services are contracted to the private sector. A few CCACs deliver services through their employees.

Funding Challenges

Most provincial governments assign responsibility for funding and delivery of care to their regional health authorities, which must adhere to provincial standards and monitor outcomes. This regionalization of home care has had both positive and negative effects. While home care and home support have become more closely integrated into a system of continuing care, they must now compete for funds at the regional level with established institutional-based programs.²⁷ Aleck Ostry, professor at the University of Victoria, points out that home support programs are particularly vulnerable because marginalized populations both receive and deliver these services. (It is primarily low-income frail female seniors and people with disabilities

who receive these services and primarily women with often limited formal education who deliver them.)²⁸

The ability of governments to choose the number and types of services and the delivery models means that home care is vulnerable to cyclical funding and political changes. For example, in Ontario, three successive majority governments (Liberal, New Democratic Party and Progressive Conservative) took different approaches to reforming home care between 1985 and 1996, each government changing the reforms undertaken by the previous one. Three different models were recommended over that relatively short time period: a brokerage model, with a coordinating agency purchasing services from existing providers; a quasi-public delivery system, whereby almost all service providers become employees of the new agency; and a managed competition model, whereby publicly funded services are purchased through a formal competitive contract process based on both price and quality.

Standards

No standards or operational objectives are legislated federally, as home care lies outside the prescribed boundary of the *Canada Health Act*. In light of changes in delivery, such as those seen in Ontario, an important question arises: is it in the best interests of those receiving and providing home care that entire systems can be changed as the political climate alters? A set of national principles, standards and guidelines would give agencies/individuals responsible for allocating resources solid direction in setting home care policies for their jurisdictions; would save time, effort and financial resources; and would provide a more stable and predictable service for home care recipients. These common

Home Care Timeline: Federal, Provincial and Territorial Initiatives

- 1984 The *Canada Health Act* identifies home care as an “extended service.”
- 1996 First Ministers (except Quebec) create the **Federal-Provincial-Territorial Council on Social Policy Renewal** to guide the social union initiative. The Council monitors work on overarching social policy issues and, as well, coordinates and supports councils that examine cross-sectoral issues such as supporting children and persons with disabilities.⁽¹⁾
- 1997–2001 The **Health Transition Fund** supports 140 projects across Canada to test and evaluate innovative ways to deliver health care services. These projects generated evidence that can be used by governments, health care providers, researchers and others in making informed decisions leading to a more integrated health care system. It funds 45 projects on the effectiveness of home care, in terms of cost and care. One project is a 15-part national study to evaluate whether home care is more cost-effective than hospital or long-term facility care; the conditions under which it is cost-effective; and the policies and programs that can be put into place to obtain cost-effective results.⁽²⁾
- 1998 Health Canada publishes the fact sheets ***Public Home Care Expenditures in Canada, 1975–76 to 1997–98***, which provide, for the first time, provincial/territorial and national expenditures for home care.
- 1999 **A Framework to Improve the Social Union for Canadians: An Agreement Between the Government of Canada and the Governments of the Provinces and Territories** is the umbrella under which governments will concentrate their efforts to renew and modernize Canadian social policy. It focuses on the pan-Canadian dimension of health and social policy systems. The primary objective of the social union initiative is to reform and renew Canada’s system of social services and to reassure Canadians that their pan-Canadian social programs are strong and secure. Its aims are to:
- ensure access for all Canadians, wherever they live or move in Canada, to

principles and standards would still allow for variation in how the service is delivered at the local level.

The federal/provincial/territorial governments have reached agreement on some home care services. (See box “Home Care Timeline.”) For example, in 2003, First Ministers agreed to provide “first-dollar coverage for [a] basket of services for short-term acute home care, including acute community mental health and end-of-life care.”²⁹ The 2004 *10-Year Plan to Strengthen Healthcare* added the specifics about the types of home care services to be covered, based on assessed need. The Ministers agreed on several areas, but did not establish standards for the services delivered.

Home Care Services Clients

Statistics Canada reported that in 2003, 5 percent of Canadians aged 18 or older — an estimated 1.2 million — received some form of home care in the past 12 months.³⁰ Approximately 648,000 were between the ages of 18 and 64 (representing 3 percent of that population), and the remainder were seniors (representing 15 percent of the over-65 population).³¹

What about those under the age of 18? The *Participation and Activity Limitation Survey (PALS)*, which is conducted by Statistics Canada every five years, collects information on adults and children up to the age of 15 whose daily activities are limited because of a condition or health problem. Results of the most recently released survey show that 202,350 children aged 0 to 14 (3.7 percent of that age group) reported a disability of some kind in 2006.³² It is not known how many of these children receive home care services, or the extent of the services they

receive. In his report, Senator Kirby estimates that children receive 15 percent of all home care services.³³

Statistics Canada compared its 2003 data on adults who use government-subsidized home care with its 1994–95 data.³⁴

- The gender ratio remained unchanged, with two-thirds of home care clients being women and one-third men.
- The average age in 2003 was 62, compared with just under 65 in 1994–95.
- Recipients spent fewer days in hospital in 2003 than they did in 1994–95.
- In 2003, more clients used nursing and personal care (52 percent compared with 39 percent) and fewer received housekeeping services (33 per cent, down from 51 percent).
- Substantially more needed help with personal activities of daily living (activities related to personal care, including bathing or showering, dressing, getting in or out of bed or a chair, using the toilet, and eating) or with moving about in their homes (up from 254,000 to 434,000).
- In 2003, a smaller percentage of those needing home care actually received it (35 percent versus 46 percent).
- The number of persons aged 18+ receiving government-subsidized home care who needed help with eating, bathing or dressing did increase, however, from 118,000 in 1994–95 to 153,000 in 2003.
- Of those who required help to move around in their home, the percentage that received government-subsidized home care dropped from 39 percent to 24 percent, although once again, the actual number of people receiving care of this nature rose from 68,000 to 74,000. This suggests that more people are requiring

essential social programs and services of reasonably comparable quality;

- provide appropriate assistance to those in need;
- respect the principles of medicare: comprehensiveness, universality, portability, public administration and accessibility;
- promote the full and active participation of all Canadians in Canada's social and economic life;
- work in partnership with individuals, families, communities, voluntary organizations, business and labour; and
- ensure appropriate opportunities for Canadians to have meaningful input into social policies and programs.⁽³⁾

2000

The **2000 Health Accord** reflected First Ministers' consensus that primary health care reform is necessary and that the First Ministers must work together to make improvements and modernize the system. Federal funding was provided for early childhood development; diagnostic and treatment equipment; and innovation and reforms in primary care; and for Canada Health Infoway to help accelerate the adoption of modern information technologies to provide better health care.⁽⁴⁾

2000–2006

The **Primary Health Care Transition Fund** arose from the Health Transition Fund and the 2000 Health Accord. It was created to support the provinces and territories in their efforts to reform the primary health care system and to support various pan-Canadian initiatives to address common barriers.

2001

The Canadian Institute for Health Information creates the **Home Care Reporting System**.

2002

Final Report of the Commission on the Future of Health Care (commonly known as the Romanow Commission), *Building on Values: The Future of Health Care in Canada*. The Commission was created in 2001 to review Canada's health care system, engage Canadians in a national dialogue on the future of health care, and make recommendations on sustaining a publicly funded health system.

Regarding home care, the Romanow Commission recommends that we recognize and develop home care as an essential service in the Canadian health care system.

Specific recommendations include using the proposed Home Care Transfer (intended to provide the foundation for an eventual national home care strategy) to ensure all Canadians have access to common home care services; revising the Canada Health Act to include three elements of home care as necessary medical services (home mental health management and intervention services, post-acute home care, and palliative home care); and providing benefits to support informal caregivers (family and friends) who deliver home care (allowing, for example, such informal caregivers to have time off work and special benefits through the Employment Insurance program).⁽⁵⁾

2002

The Report of the Standing Senate Committee on Social Affairs, Science and Technology (the Kirby Report), *The Health of Canadians — The Federal Role*, contains recommendations on expanding public health care insurance to include coverage for catastrophic prescription drug costs, immediate post-hospital home care costs, and costs of providing palliative care for patients who choose to spend the last weeks of their lives at home. It also contains recommendations for a caregiver tax credit and job protection for the caregiver, focusing on those giving palliative care.

2003

Through the **First Ministers' Accord on Health Care Renewal**, the First Ministers agree to provide "first-dollar coverage for [a] basket of services for short-term acute home care, including acute community mental health and end-of-life care."⁽⁶⁾ They also agree that access to these services should be based on an assessment of need, and that the services be available by 2006. The federal government agrees to establish compassionate care benefits and job protection for Canadians who need to leave their jobs temporarily to care for a gravely ill or dying child, parent or spouse.

2004

10-Year Plan to Strengthen Health Care adds the following specifics about the types of home care services to be covered, based on assessed need:

- short-term acute home care after discharge from hospital, consisting of two

help, but only the people most in need are receiving it.

- The likelihood that people with specific chronic conditions would receive government-subsidized home care did not change significantly.
- More of those receiving subsidized home care suffered from urinary incontinence, adding to the burden of care (8 percent to 17 percent).

It is difficult to obtain up-to-date and comprehensive statistics on users of home care. The numbers vary for several reasons: there are limited provincial tracking systems; home care services can be paid for by both public funds and private funding; and the anonymity of family caregivers and other volunteers. Statistics Canada does not collect data on those between the ages of 15 and 18 and those receiving voluntary care. Furthermore, all provinces and territories have distinct home care programs, which provide different types of services and levels of care in the home. Beyond this, all jurisdictions have different reporting systems.

Home care is a growing component of our health system.

It has been noted that the number of home care recipients increased by almost 100 percent between 1995 and 2006.³⁵ Why the growth?

- Clients/patients often prefer to receive care in their own home.
- Home care has garnered a high degree of support in the health care field and from the general public.³⁶ The majority of Canadians (80 percent) support the development of more home and community care programs as a means of strengthening the health system.³⁷ Government-funded studies have also

come out in support of a more prominent role for home care.

- Canada's population is aging. One out of seven Canadians is over the age of 65. In 2006, this cohort accounted for a record high of 13.7 percent of the total population, up from 13.0 percent in 2001 (nearly double the proportion of 7.7 percent in 1956). Between 2001 and 2006, the number of people aged 80 years and over surpassed the 1-million mark. Additionally, the number of centenarians rose sharply.³⁸
- Canada faces an epidemic of chronic disease,³⁹ the five most prevalent being cancer, cardiovascular disease, chronic pulmonary disease, mental illness and musculoskeletal conditions. One in three adults in Canada, or close to 9 million people, has a chronic disease. More than one-third of these have multiple long-term health problems. Chronic conditions are more common among older Canadians (77 percent of people 65 years or older have at least one chronic condition).⁴⁰
- Governments perceive home care to be less expensive than other settings of care.
- Technology permits care to be given at home for a wide range of conditions.
- In some cases, home care is necessary because patients are being discharged more quickly as hospitals attempt to clear beds for the next patient.⁴¹ Without question, hospital stays have declined: the number of hospital beds has been reduced, and day surgery is more prevalent. In 2003, recipients of government-funded home care services spent an average of 8.6 days in hospital, compared with 13.4 in 1994–95.⁴²
- There has been an overall shift away from long-term home care to short-term home care, resulting in greater turnover of recipients, and, therefore higher numbers of recipients. (More people does not mean more care, however.)

weeks of case management, intravenous medications related to the discharge diagnosis, and nursing and personal care;

- short-term acute community mental health home care, consisting of two weeks of case management and crisis response services; and
- end-of-life care, consisting of case management, nursing, palliative-specific drugs, and personal care.

Health ministers agree to explore the next steps to fulfilling the home care commitments described above, including plans for staged implementation and annual reporting to their citizens, and to reports to First Ministers by December 31, 2006.

2004 **Compassionate Care Benefit** is introduced by the federal government.

2007 Health ministers report that all provinces and territories have taken steps towards fulfilling their commitments for home and community care services as described in the 2004 Accord.⁽⁷⁾

Footnotes and Sources:

- (1) Government of Canada, "Social Union Framework Agreement Review." N.d. Retrieved May 1, 2008, at: http://www.unionsociale.gc.ca/menu_e.html.
- (2) Health Canada, "Health Transition Fund." N.d. Retrieved May 1, 2008, at: http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/finance/htf-fass/index_e.html.
- (3) Government of Canada, "A framework to improve the social union for Canadians: An agreement between the Government of Canada and the governments of the provinces and territories," News release, Feb. 4, 1999. Retrieved May 1, 2008, at: http://www.unionsociale.gc.ca/news/020499_e.html.
- (4) Department of Finance, "Federal Transfers in Support of the 2000/2003/2004 First Ministers' Accords." Retrieved May 1, 2008, at: <http://www.fin.gc.ca/fedprov/fmAcc-eng.asp>.
- (5) Makarenko, Jay, Romanow Commission on the Future of Health Care: Findings and Recommendations, April 2007. Retrieved May 1, 2008, at: <http://www.mapleleafweb.com/features/romanow-commission-future-health-care-findings-and-recommendations#recommendations>.
- (6) First Ministers of Canada, First Ministers' Accord on Health Care Renewal, 2003, pp. 3–4.
- (7) Health Council of Canada, Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada. (Toronto: Health Council, 2008), p. 13.

For Kids, There's No Place Like Home

The Rotman Award for Pediatric Home Care Innovation

— created by the SickKids Foundation in 2005 and made possible by a donation from Janis Rotman — signals that home care is being publicly acknowledged as a vital component of health care for all ages.

Across Canada, the number of children and youth with acute and continuing care needs in the home and community is growing at a rapid pace as a result of technological changes and health system restructuring. The Rotman award recognizes and supports outstanding home and community health care programs that serve Canadian children, youth and their families.

In 2006, the Intensive Ambulatory Care Service (IACS) of the Montreal Children's Hospital won the award.

Since the 1960s, it has concentrated its efforts on getting children home as quickly and as safely as possible, even those with chronic or complex illnesses that require specialized care. The IACS team provides the necessary support — including oxygen therapy or palliative care — for keeping 500 children with special needs in their home. The IACS also focuses on providing training and educational opportunities, such as in basic tracheostomy care and vascular access (ports and picc lines), to those who care for children and youth in the home or community. Whatever the diagnosis, the IACS prides itself on its comprehensive, coordinated care, with nurses as case managers and a multidisciplinary team approach.

The 2007 winner was **Edmonton's Capital Health Home Care Children's Services**. Like the IACS, it provides both short- and long-term pediatric home care — to 425 individuals each month. Program Manager Laurene Black said, "Capital Health's program was one of the first community-based pediatric home care programs in Canada. Our model recognizes that children do best in their own homes with the appropriate and adequate supports in place for the family." To that end, Capital Health undertook a pilot project to provide more skilled caregivers for children with complex health needs. It provided special training for health care aides, all of whom indicated that they would be willing to work nights, and assigned them to a sick child, thus providing continuity of care, assurance of competence and respite for the parents.

In 2008, the Children's Treatment Network of Simcoe York joined the winners' circle. Why? It is the first home care delivery model to link more than 45 health care, education, recreation and social services agencies to permit a team approach to each of the 4,500 children with multiple disabilities that the Network serves. It therefore facilitates the often complex navigation through

Demand for home care is expected to continue to increase as the large cohort of baby boomers enters and moves through their senior years. Although home care exists at the margins of what Baranek et al. call "the medicare mainstream," it is emerging as a vital component of the health system.

Government spending on home care has risen, but it remains a small percentage of the health care budget.

Many jurisdictions have made efforts to improve access to home care. Universally accessible, publicly funded home care programs have been initiated and/or expanded, but all are targeted to specific populations.⁴³ (See appendices 1 and 2 for an overview of each province and territory's visions and targets for home care, and selected activities to expand access to home care services.)

The Canadian Institute of Health Information (CIHI) provides key data on government spending on home care.

- Government spending on home care grew from \$1.6 billion in 1994–95 to \$3.4 billion in 2003–04, representing an average annual growth of 9.2 percent.
- Home care spending constituted only 4.2 percent of total government health spending in 2003–04, up from 3.1 percent in 1994–95.
- The number of patients using government-subsidized home care increased from 23.9 per 1,000 in 1994–95 to 26.1 per 1,000 in 2003–04, representing an average annual increase of 1.0 percent. Over those years, spending on home care increased faster than the number of patients, suggesting that, in general, home care users each consumed more resources in 2003 than

they did a decade previously. In the 1990s, many people were cut off from preventive care services and the funds were reallocated to those needing a higher level of care. (See box “For Kids, There’s No Place Like Home.”)

- In 2003–04, provincial and territorial government spending on home care averaged \$105.30 per capita.

CIHI separates home care spending into two components: *home health*, which includes professional services such as nursing care, and *home support*, which includes other services, such as personal care, housework, meals, shopping and respite care. Government spending on both components has increased over time: in 2003–04, per capita spending was \$56.95 for home health and \$60.10 for home support (up from \$32.41 and \$41.95, respectively, in 1995–96).⁴⁴

In Canada, private spending on home care outstrips public spending.

CIHI notes that professional home health services accounted for an increasing share of spending on home care services, rising from 43.3 percent in 1995–96 to 48.6 percent in 2003–04.⁴⁵

The Health Council of Canada estimates that in 2005, 2–3 percent of Canadians received government-subsidized home care and 2–5 percent paid privately for home care services.⁴⁶ (See Chart 1, “Use of Home Care Services Funded by Government and Not Funded by Government.”) The proportion of private versus public services varies by province. In a 2003 Statistics Canada survey, for example, 65 percent of home care recipients in Manitoba indicated that they had some or all of their care covered by public funding, compared to 42 percent in British Columbia.⁴⁷

the health care, education and community systems. And the best thing about the model? It is easily reproducible.

The IACS, Capital Health and Children’s Treatment Network are in the vanguard of an ever-strengthening movement to provide more home care to children — and more respite to their parents.

Sources:

Black, Laurene, “The Role of the Health Care Aide in a High Needs Pediatric Population in the Community.” Presentation to the symposium “Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada,” held Feb. 20, 2007. Retrieved April 1, 2008, at: <http://www.crnc.ca/events/download/LaureneBlack-February20thpresentation.pdf>.

Capital Health, “Capital Health Home Care Children’s Services wins national award.” News release, Aug. 15, 2007. Retrieved April 1, 2008, at: http://www.capitalhealth.ca/NewsAndEvents/Features/2007/Home_Care_Childrens_Serv.

The Globe and Mail, “Rotman Award Plays Key Role in Pediatric Home Care.” Leadership in Children’s Health: An Information Feature to The Globe and Mail, Nov. 29, 2006. P. E3. Retrieved April 1, 2008, at: http://www.sickkidsfoundation.com/news/downloads/globeandmail_nov27.pdf.

McGill University Health Centre, “Rotman Award recognizes MCH efforts to care for children with complex illnesses in their homes rather than in hospital.” News release, June 12, 2006. Retrieved April 1, 2008, at: <http://www.muhc.ca/media/news/?ItemID=20533>.

Patel, Hema and Isabelle St. Sauveur, “The Intensive Ambulatory Care Service: A Medical Home for Children with Complex Medical Needs.” Presentation at the symposium Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada, Feb. 20, 2007. <http://www.crnc.ca/events/download/HemaPatelandIsabelleStSauveur-February20thpresentation.pdf>.

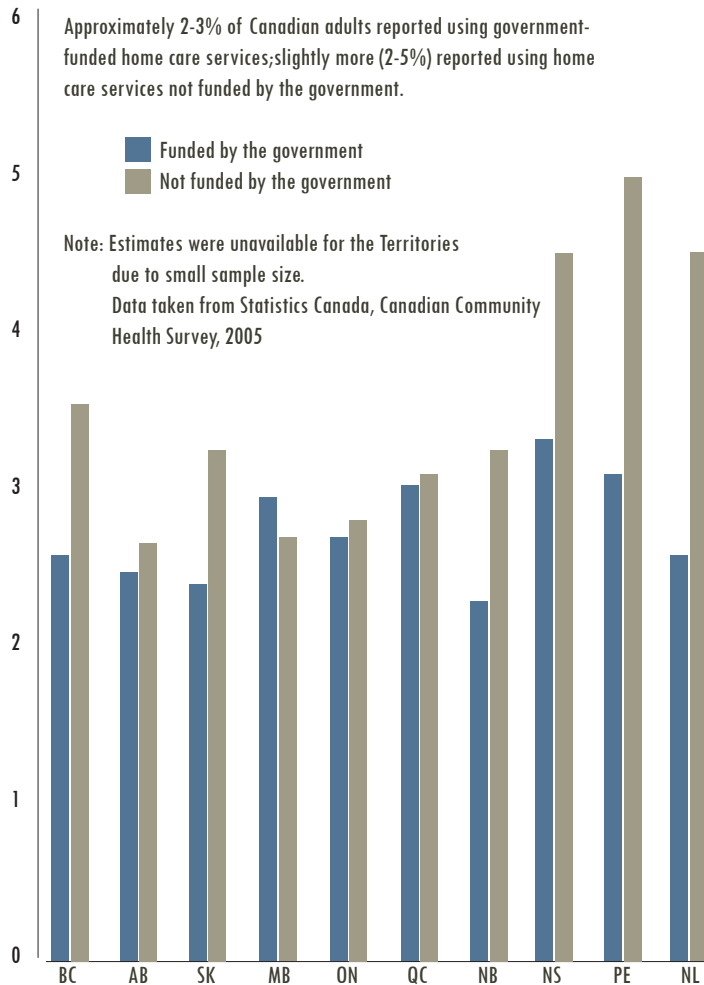
SickKids Foundation, “Children’s Network of Simcoe York awarded \$100,000 prize for creating integrated homecare model.” News release, June 16, 2008. Retrieved Jan. 9, 2009, at: <http://www.ctn-simcoeyork.ca/resources/Rotman%20Award%20Release%202008%20Final%20for%20web%20posting.pdf>.

Total expenditures on home care exceed what is reported.

Actual spending on home care identified by CIHI may be twice the \$3.4 billion identified. Why? First, more formal care is delivered privately than publicly. Second, the bulk of care is delivered by informal caregivers. If one were to calculate a minimum wage for all the volunteer hours devoted to care,

estimated to be at least \$6 billion,⁴⁸ the total amount devoted to home care in Canada could approximate \$13 billion.

Chart 1: Use of Home Care Services Funded by Government and Not Funded by Government



Source: The Health Council of Canada. Originally appeared as figure 9 in *Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada*. (Toronto: Health Council, 2008). Reproduced with permission.

Some Conclusions

What conclusions can we draw from this section?

1. The number of people receiving home care has risen and is expected to continue to do so.
2. The people who are receiving subsidized home care generally require a higher level of care.
3. In looking at the health care budget as a whole, home care remains a small component.
4. Of the component dedicated to home care, the emphasis, or priority, is on post-acute care rather than long-term care that is focused on maintenance of skills and preventive care.
5. The provision of home care appears to be shifting from the public to the private sector, and, in cases where clients are unable to pay for private care or it is unavailable, the informal caregiver must shoulder more responsibility for care.

The need for home and community-based care is growing but the capacity to manage that need is still being developed. This has placed a significant burden of care on individuals, their families and volunteer caregivers.

— Canadian Institute for Health Information⁴⁹

Gaps Opportunities

Identified Gaps — and Opportunities

A number of gaps exist in the realm of home care — related to groups of individuals, specific services, and links between services. These gaps indicate that home care is not yet fully integrated into the continuum of care and that we are not utilizing home care to its greatest possible extent.

Three to Four Per Cent of Seniors

The Health Council of Canada noted that, in 2005, 3–4 percent of seniors reported that they need home care but do not receive it. (See box “Preventive Home Visits.”)

Those Who Need Long-Term Home Care

Governments have been focusing on short-term post-acute home care. In making this decision, they have been influenced by two major reports, both published in 2002: *The Final Report of the Commission on the Future of Health Care, Building on Values: The Future of Health Care in Canada* (the Romanow Report) and the *Report of the Standing Senate Committee on Social Affairs, Science and Technology* (the Kirby Report).

Both reports have been criticized for their limited home care recommendations. The Romanow Report, while recognizing home care “as the next essential service,” identified as priority areas home care for mental health case management and intervention, post-acute rehabilitation and medical care, and palliative care. With the exception of mental health, the Romanow recommendations focused on the short-term medical side of home care.



The Kirby Report made recommendations regarding home care similar to those of the Romanow Report. It urged a national program to provide publicly funded insurance coverage or post-acute home care, as well as coverage for a national palliative home care program.

Both the Kirby and Romanow reports emphasized the acute side of home care. In doing so, they did not give priority to those

who are frail and elderly, who suffer from dementia, who require ongoing care due to co-morbidities; or who are physically and/or mentally disabled.

Children

Approximately 15 percent of home care clients are children and youth. Data on children are lacking, so it is not known how much of the care received is medical in nature and how much is devoted to ongoing care and development. What is known is that more children are surviving illnesses that previously would have been fatal, and that children with developmental problems who may well have been institutionalized in the past are now living in their homes and are eligible for home care services. These services are often vital not only for the children's health but also for their development, as well as for the social support of their families.

In 2006, the Canadian Home Care Association gathered provincial/territorial information on governance, programs and services, access, population, and challenges, innovations and plans. Using this information, it produced a CD-ROM titled *Home Care for Children with Special Needs: An Environmental Scan Across Canadian Provinces and Territories*. (See box "Home Care for Children with Special Needs.")

Findings include the following:

- National data are required. Most jurisdictions do not gather information about the age of children receiving home care services or their diagnoses.⁵⁰
- Home care policies are aimed at seniors and do not specifically address children.⁵¹
- Home care is different in nature for children with special needs. "Many of the

Preventive Home Visits

Denmark's Ministry of Social Affairs passed a law in 1998 obliging municipalities to offer home visits twice a year by a professional to all citizens aged 75 and older. Denmark has found that older and frail persons wait too long to ask for care, by which point they have declined in health. Visits should ideally be made by the same person, who can note changes over time.

These visits serve multiple purposes. They:

- initiate contact or facilitate encounters with older persons who may not request medical attention as expeditiously as they should;
- help older people to help themselves with the aim of remaining well and independent for as long as possible;
- seek to avoid or prevent functional decline;
- identify safety issues in the home, with an eye to preventing such things as falls;
- raise awareness of community services and programs; and
- facilitate adjustment of home care arrangements as needed.

Denmark has found that these visits have reduced hospital admissions by 19 percent, and admissions to long-term care facilities have declined by 31 percent.

Sources:

Swane, Christine, "As Good as It Gets — in Denmark: From Preventive Home Visits to Reminiscence and Nature in Dementia Care." Presentation at the Re-Imagining Health Services: Innovations in Community Health Conference, Vancouver, British Columbia, Nov. 7, 2008.

Vass, Mikkel, et al., *Older People and Preventive Home Visits* (Denmark: AgeForum, September 2006). Retrieved Jan. 14, 2009, at: <http://www.aeldreforum.dk/wm141970>.

typical home care services available to the adult population, such as meals, home support, and day programs, are not provided to children as it is assumed that these are parental responsibilities.”⁵²

- There is income testing for families for home care services in six provinces/territories. There are generally limits and income considerations for families in relation to equipment, medications and supplies required to provide care in the home.⁵³
- A physician order is a requirement for access to home care for children in British Columbia, Saskatchewan, Quebec and New Brunswick.⁵⁴
- Respiratory therapy services, speech language pathology and nutrition services are not typically offered to children at home. Other therapy services are offered to a limited extent. Ontario is the exception; it offers all therapies except respiratory.⁵⁵
- It is complex and difficult for parents and guardians of children with special needs to gain access to services. There are many ministries involved, and multiple points of access (health, education [as some home/community care for children is given through the schools] and children’s services).⁵⁶
- Wait lists can be lengthy, both for diagnosis and for services. The Canadian Home Care Association points out that in the Baffin and Kitikmeot regions of Nunavut, a child may wait six to twelve months for occupational therapy and physical therapy and up to two years for speech language pathology services.⁵⁷
- Home care services and programs for children are not consistent between rural and urban settings. This is due to the fact that trained staff are not generally available in rural settings.
- Respite services, offered by all provinces and territories, are particularly important for parents of children with special

Home Care for Children with Special Needs

The Canadian Home Care Association defines children with special needs as “those who require a network of health, education, social and other services in order to live with long-term health concerns in their homes and communities. The children in this population have a wide range of physical, developmental or mental health issues, congenital or acquired. This includes: children who are chronically ill, disabled (mental and/or physical), or developmentally delayed; children with a psycho-social problem, complex care needs; those who are medically fragile, technology dependent, physically or mentally challenged. Conditions may vary from mild to severe, occur in multiples or singly, and include among other conditions asthma, blindness, cancer, cerebral palsy, diabetes, head injury, heart, kidney, or liver disease, deafness, rare syndromes, seizure disorders and spina bifida.”

Source:

Canadian Home Care Association, “Home Care for Children with Special Needs: An Environmental Scan Across Canadian Provinces and Territories.” CD-ROM, Sept. 2006.

needs. In many cases, the children will have their conditions for life and will require lifelong care. Parents must often juggle the care of more than one child, adding to the burden of care.

- The transition from home services to school services and from children’s services to adult services is often problematic.⁵⁸

Home care is very important for children with special needs as they are attached to and highly dependent on their parents, and institutionalization is not the preferred option for them. In 2002, Saskatchewan introduced the *Children with Highly Complex Medical Care Needs* program to assist the health regions in funding the direct care costs of children (up to the age of 22) with exceptional home care needs (in terms of both complexity and intensity) in cases where the child would otherwise have to live in a facility.⁵⁹ Although outstanding programs such as this exist, the findings of the Canadian Home Care Association suggest

that there are common issues that need to be addressed, chief among them being a lack of information on diagnoses (vital for proper educational planning); lengthy waiting lists; differences in services offered; and difficulties associated with transitions.

Those Who Are Dying

The Romanow and Kirby reports emphasized palliative care. Federal, provincial and territorial governments in the 2003 and 2004 accords made commitments to providing two weeks of palliative care in the home, where circumstances permit. However, a progress report undertaken by the Quality End-of-Life Care Coalition found that 60 percent of deaths still occur in hospitals, while most people have indicated that they would prefer to die at home.⁶⁰ Though we have taken several strides forward in the care of dying persons, there is still considerable work to be done in this field.

First Nations and Inuit People

The federal government is responsible for the health care of First Nations and Inuit people, whose senior populations are expected to triple by 2026.⁶¹ The responsibility for home care services is divided among federal departments.⁶²

Health Canada launched the *First Nations and Inuit Home and Community Care* (FNIHCC) program in 1999. Developed through collaboration and consultation with Aboriginal communities, the program provides various health-related home care services, including case management and nursing care. In addition, the *Assisted Living/Adult Care* program, administered by Indian and Northern Affairs Canada, provides support services to elderly or disabled First

Nations persons living on reserves. Services provided include homemaker, foster care and institutional care services.

Health Canada and Indian Affairs programs are relatively new and provide basic services where none existed before. There is no income testing nor direct fees, and supplies and equipment are provided free of charge. Yet, the programs are not meeting all the home care needs of Inuit and First Nations communities.⁶³ The FNIHCC program is limited in its home care service provision by the fact that it is currently available Monday through Friday only.⁶⁴ Services not funded are numerous: facilitation and linkages or rehabilitation and therapy services, including speech language pathology, social work, respiratory therapy and dietetics; respite care; adult day care outside the home; meal programs; mental health home-based services for long-term psychiatric clients and clients experiencing mental illnesses; traditional counselling and healing services; home-based palliative care; social services directly related to continuing care issues; and specialized health promotion, wellness and fitness.⁶⁵

In 2004, the Government of Canada and First Nations and Inuit organizations undertook research to gain a better understanding of existing home- and facility-based continuing care services in Aboriginal communities. They surveyed almost 500 clients who were receiving continuing care services in their own home or in a facility in eight First Nations communities in Manitoba and Quebec, and in three Inuit communities in Nunavik. The survey revealed some interesting findings: home care is used by clients with a wide range of care needs but is used mostly by those with lower care needs; existing facility services are used by all clients but more frequently by those with higher acuity; First Nations and Inuit continuing care clients tend to be younger

than clients from the general Canadian population; and First Nations and Inuit persons of all ages appear more likely than other Canadians to be continuing care clients.

Several major gaps in continuing care services in Aboriginal communities were identified:

- Families and caregivers require better evening and weekend access to home and community care and better overall access to respite care.
- The formal system should be structured to support families in managing their care loads.
- Continuing care services should be designed to deliver care to all types of clients, including those with high-level care needs (e.g. long- and short-term facility-based care).
- Supportive housing could fill some of the gaps at lower levels of care.
- Funding issues need to be addressed to meet the increased demand for care and higher level care needs. Several factors would require consideration: case mix, culture and language requirements, community size and location.

The First Nations and Inuit home care issue will continue to be important. Considering the anticipated sharp rise in the number of elderly persons, policy-makers have a window of opportunity to develop the necessary programs before the crunch hits less than two decades from now.

Those Suffering from Mental Illness

Some provinces offer home care to persons with a mental illness recently discharged from hospital.⁶⁶ But home care could play a larger role in helping persons with a mental illness. As evidenced by the *Health Transition Fund's Home-Based Program for Treatment*

of Acute Psychosis, home care reduced hospitalizations and hospital readmissions among those receiving home care services, although it achieved only modest savings. This suggests that patients can benefit when home care planning becomes part of hospital discharge planning. Home care can reduce dependence on hospitals for treatment, particularly among mentally ill persons who experience the revolving door syndrome (cycling in and out of hospital).

Three barriers currently stand in the way of a greater role for home care in mental health: changing the fee-for-service schedules for psychiatrists, which currently pay more for hospital inpatient visits than for office visits; changing the perception that the primary goal of home treatment is to save money, and finding experienced mental health workers to provide the required specialized care at home.⁶⁷

Legislation that Addresses Home/Community Care on a Pan-Canadian Basis

Legislation to deal with home care on a pan-Canadian basis does not exist and is much needed. Such legislation could provide a specific federal/provincial fiscal arrangement on home care that would allow the provinces and territories to integrate home care into the continuum of care but adapt it to suit their own particular needs. Legislation could also identify standards of care and mechanisms for accountability.

Equitable Services Across Canada

The 2004 Accord provided funding for two weeks of post-acute care home care, but as the Health Council of Canada recently pointed out, two weeks “is still too modest”⁶⁸ and “progress in ensuring access to broad,

equitable home care services has been slow and piecemeal.”⁶⁹ Variations exist in many aspects of home care across the country: the application of co-payments and income testing; user fees; range of services; publicly funded services; residency requirements; and client payment of supplies, equipment and drugs used in home care.

There are also inequities between the services available in rural/remote locations and urban areas. Respondents to a survey undertaken by the CHCA on the delivery of home care services in rural and remote communities identified the following gaps: health human resources (lack of physicians, nurses, practitioners and home support personnel); difficulties related to travel, transportation and access; and limited local resources, resulting in unnecessary use of acute facilities.⁷⁰

Appendices 3 to 6 present information on the disparities throughout the country. Appendix 3 identifies the differences across Canada in terms of co-payments and income testing. Appendix 4 shows the services not offered through home care. Appendix 5 compares the differences in coverage of drugs, supplies and equipment. A recent comparison of provincial prescription drug plans and the impact on patients’ annual drug expenditures published in the *Canadian Medical Association Journal* finds that considerable discrepancies exist across the country in publicly funded provincial drug plans, leading to great variations in costs to patients. It concludes that “although current provincial drug plans provide good protection for isolated groups, most Canadians still have unequal coverage for outpatient prescription drugs.”⁷¹ This would include many people receiving home care services or treatment. Finally, Appendix 6 highlights the different limits to home care provision among the provinces and territories. In terms of residency requirements for home

care services, the differences are minor. British Columbia requires three months of continuous residency while other provinces and territories specify that home care applicants hold provincial health insurance coverage, or be in the application process.

Information and Communications Technology, Electronic Health Records and Telehealth

Research shows that information and communications technology (ICT) — electronic health records, telehealth, home telemonitoring devices, electronic reminders — is already making a big difference in the lives of home care clients and has the potential to play a greater role.

Today, ICT helps clients to:

- remain at home with greater peace of mind;
- self-monitor and manage their conditions; and
- make fewer visits to hospital.

It helps providers to:

- monitor and manage the conditions of patients with chronic disease and in post-acute care;
- increase the number of patients they can monitor, and thereby boost their productivity;
- access and exchange information more efficiently;
- decrease paperwork;
- collect data and evaluate it, and be alerted promptly when conditions change;
- reduce errors, duplication and administrative costs;
- obtain diagnostic results more quickly; and
- improve the quality and coordination of care.⁷²

Despite the promise and potential of ICT, a 2006 study by the U.S.-based Commonwealth Fund indicates that Canada falls behind other developed countries in its use. For example, only 23 percent of primary care physicians in this country have electronic medical record systems, compared to 98 percent in the Netherlands, 92 percent in New Zealand and 89 percent in the United Kingdom.⁷³ Canada Health Infoway, the agency mandated to foster the development of electronic health information systems, aims to provide 50 percent of Canadians with an accessible electronic health record by 2010 but is finding this goal to be a challenge.

Telehealth, however, is beginning to gain momentum, and is proving to be a useful tool in facilitating home care. Changes are occurring quickly. At the time of writing of this brief, Canada's telehealth system consists of the following services:

- In British Columbia, the BC NurseLine offers support to residents, including those providing palliative care, during the off-hours of 21:00 to 8:00.⁷⁴ Since 2003, it also offers the support of a pharmacist.
- Alberta has introduced telehealth into home care, primarily to support chronic care patients.
- Saskatchewan currently is exploring its use for rural and remote care. In that province, telehealth is used for education, but not used in the delivery of home care.⁷⁵
- Telehealth (video technology and real-time monitoring) has been introduced in several regions of Manitoba primarily to support chronic care and palliative care patients, and for wound care.⁷⁶
- In Ontario, tele-homecare is being used as a clinical delivery tool in a few locations for palliative acute, chronic and rehabilitation care needs.
- Quebec has initiated pilot projects involving telehealth in home care.
- In New Brunswick, telehealth has been introduced for palliative care, acute care, chronic care and rehabilitation patients. The telehealth technology includes store and forward technology, video-technology and real time.⁷⁷
- Nova Scotia has not yet adopted telehome care but offers it on a limited trial basis.⁷⁸
- PEI has introduced telehealth into home care in one site.⁷⁹
- Newfoundland and Labrador has introduced telehealth to support Healthline Telerriage and has developed a *Telehealth Strategic Plan* in which its role in home care is a priority.⁸⁰
- Nunavut uses telehealth technology to provide case management services, for rehabilitation services to a certain extent, and for communication purposes among members of the health care team.⁸¹
- In Yukon, telehealth has been introduced for home care to support discharge from hospital to community. Telehealth technology includes store-and-forward technology, video technology, and real time and web-based technologies. Canada Health Infoway is providing funds for enhanced telehealth, including modules in the home care program for direct linkages to the community for care planning and to support community providers. There are linkages to the University of Alberta and two rehabilitation centres for staff training and support.⁸²
- The Northwest Territories uses telehealth technology to a limited degree to support home care services, including acute care, chronic care, palliative care and rehabilitation. Telehealth technology includes store-and-forward technology, video technology, real time and web-based systems.⁸³

Case Management

Case management is an interdisciplinary, collaborative process that assesses, plans, implements and evaluates the services required to meet an individual's health needs.

Commonly a nurse or social worker, the case manager is typically part of a multidisciplinary team and is responsible for using health resources in the most effective manner. Although many believe that case managers should be assigned only to the most complex patients, there is general consensus that the role of case manager is a critical one: case managers promote the best health interests of the client; are knowledgeable about community resources and how to access them; and ideally reduce the need for medical appointments and acute care interventions, including visits to emergency departments.

Case management is key to integrated care, especially with complex patients, enabling them to move seamlessly from the physician's office, long-term care facility or hospital to home with appropriate care and follow-up. Case management is not without its challenges, however. There is need for greater communication and collaboration between case managers and providers, as well as a system to ensure that clients receive prescribed care.

An initiative of the *Primary Health Care Transition Fund* pioneered one way to overcome these challenges, thereby enhancing care and making more optimal use of health human resources. It paired case managers with family physicians, designating them as part of the health care team. This arrangement proved beneficial to all concerned: the physicians felt more supported and had a lighter workload; the case managers were better

able to coordinate care; and the patients' conditions improved. (See the section "*The Primary Health Care Transition Fund*.") This arrangement is now being promoted as a national model.

The Quality End-of-Life Care Coalition of Canada has underscored the importance of 24/7 case management for palliative home care. In 2006, the Canadian Hospice Palliative Care Association issued *The Pan-Canadian Gold Standard for Palliative Home Care*, and two years later the Coalition issued a progress report. It assessed the progress made by several jurisdictions (all provinces except Quebec, the three territories and Veterans Affairs Canada) in giving Canadians access to a range of palliative home care services (case management, nursing, personal care, pharmaceuticals). It noted that all jurisdictions had made significant progress. Yet only six (British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Nova Scotia) have policies on providing 24/7 nursing and personal care services and only four (Saskatchewan, Ontario, New Brunswick and Newfoundland and Labrador) have policies ensuring round-the-clock access to case management.

Targeting and Integrating Home Care with Other Parts of the System

To ensure that home care does not become an add-on component of health care, home care must be integrated with other parts of the system. Integrated care requires linkages, coordination (usually by a case manager) and access (the more seamless, the better). In caring for seniors and other vulnerable groups, there are degrees of integration. Excellent examples of integrated care can be found in Canada and abroad.

Marcus J. Hollander, a health researcher and acknowledged expert on home and community care, believes that Canada is a leader in developing models of integrated care. The following examples indicate the range of models that has developed in this country:

- The *Veterans Independence Program*, offered by Veterans Affairs Canada, provides long-term maintenance and preventive care to veterans, thereby allowing them to remain in their home as long as possible. (See the section “The Continuing Care Research Project.”)
- PRISMA (See the section “Grappling with Funding and Integrating Home Care.”)
- For higher needs care, Edmonton’s *Comprehensive Home Option for Integrated Care for the Elderly (CHOICE)* brings the people to care rather than vice versa. It provides transportation, an adult day centre, congregate dining, social activities, exercise activities, medication monitoring, health education and respite care.
- *Système de soins Intégrés pour Personnes Âgées fragiles (SIPA)* is a community-based system of care that assumes responsibility for the health outcomes, utilization and costs of services for the population of frail elderly persons in a specific catchment area. Providing the full range of social and health care services, SIPA integrates social and health care through case management, multidisciplinary teams, and care guidelines and protocols based on best practices.⁸⁴
- Ontario’s *Home at Last* provides care from hospitals to home. It links hospitals, CCACs and community service agencies; expedites timely hospital discharge; aims to minimize readmission; provides supportive services (e.g. transportation, escort, medication, meals); and assists with future care planning.

- New Brunswick’s *Extra-Mural Program*. (See box “New Brunswick’s Extra-Mural Program: Lessons Learned,” in the conclusion of this brief.)
- Prince Edward Island’s *Integrated Palliative Care Initiative* was recognized by the Health Council of Canada in 2005 as a leading practice because of its collaborative practice among disciplines and care sites, coordinated entry to the programs and client- and family-focused approach, and for its use of a common palliative care assessment tool.⁸⁵

Challenges to integrating home care include developing a coordinating mechanism; identifying and targeting those who need integrated care; ensuring smooth access; providing case management; creating coordinated provider networks; educating providers; and making a persuasive business case to policy-makers.⁸⁶

Conclusions

Home care challenges and opportunities exist across the country. Clearly, there are differences and inequities, and the needs of some population groups and cohorts are better addressed than others. Therefore, it makes greatest sense to strategically target our efforts to those with unmet needs: people who need long-term home care, who are dying, who are children, or are First Nations and Inuit.

We are not short of solutions. Here is where we could begin:

- *Optimize the skills of case managers*. This would help ensure that clients obtain maximum benefit and would make the most effective use of the health system.
- *Focus on palliative home care*. There is a large discrepancy between the number

of people who prefer to die at home and the number who actually do so. We recognize that it is not always possible or appropriate for people to die at home, however, for those who can die with comfort at home, it should become the norm.

- *Use technology.* Given Canada's large geography, aging population and shortage of health human resources, it is in our best interests to optimize technology.

Doing Things Differently

Australia: Doing Things Differently Down Under

Australia shares many of our home care challenges but is addressing them differently. It was chosen as a comparator because it is similar to Canada in many respects and faces many of the same challenges. Other countries, such as the United States and the European Union countries, have very different health systems; larger, more cohesive populations; or smaller geographical areas.

Like Canada, Australia is a developed nation with a large geography; a relatively small, far-flung population concentrated around the coast rather than the interior; an Aboriginal population; a parliamentary democratic government, with local, state/territorial and a national government; and a public health system that ranks among the top 12 Organisation for Economic Co-operation and Development (OECD) countries.

Australia has a national home care system that has been in place since 1985. Prior to that year, each state offered home care services, but as is currently the case in Canada, they differed in scope and quality. Having a national home care system has not solved all of Australia's home care problems. Discrepancies and disparities persist. As is the case here, more Australians require home care services than receive them. Concerns have been expressed about the cost of funding home care for young people with mental and physical disabilities, who, unlike frail elderly persons, can be expected to receive home care for decades.⁸⁷

A 2005 Senate Committee report reviewing Australia's care of the aged population noted the lack of integrated care across the continuum — and urged that this be addressed and that policy be built upon the best practices and successful initiatives of the various Australian states.⁸⁸



Despite these problems, which Canada and many other countries share, Australians have been deliberate in developing their national home care system. They:

- focused on persons living in the community who need maintenance and support services to remain at home, such as persons with moderate, severe or profound disabilities;
- targeted five groups of people who have difficulty accessing services, including Aboriginal Australians, people from culturally and linguistically diverse backgrounds, people with dementia, people who live in rural or remote areas, and financially disadvantaged persons;
- clearly divided responsibilities between the national and state/territorial governments, identifying post-acute and palliative care as extensions of hospital services, and therefore as state responsibilities;
- encourage user fees but do not refuse services to those who cannot pay;
- developed an *Aged Care Assessment Program* that assesses people who either need to enter residential care or need high levels of support to remain at home;
- focus on strategic alliances between government and provider agencies. (Governments often work directly with public agencies to build capacity, focusing on consolidating and building more services using current providers in order to create larger home care organizations that are managed efficiently and can benefit from economies of scale.);
- offer educational, moral and financial support plus respite relief to caregivers. (See the section “How We Compare Internationally in Our Support for Carers.”);
- have avoided a public/private debate concerning the delivery of services;
- focus on planning, establishing three-year plans with the states and territories, taking into account the unique features of the population to be served in each region of the country and the opinions of key stakeholders in the region/state;
- jointly set targets for service provision;
- collect data on who receives services and on the nature and extent of services received, and use this information for planning purposes. (There is a minimum data set, to which all agencies are expected to contribute information and for which they receive help to do so properly.);
- base policy decisions on evidence of what works; and
- have never lost sight of a national home care system, while acknowledging state, territorial and regional differences. The Australians’ aim is to achieve equity in the provision of services across the country by 2011.⁸⁹

Australia has also developed innovative programs to support those who need care and their caregivers.⁹⁰ These include:

- *Community Aged Care Packages* (started in 1992), which promote aging in the home rather than in a facility;
- *Extended Aged Care at Home* (EACH) packages, which were introduced by the Australian government in 2002 after a pilot program showed that it was feasible and cost-effective to provide high-level nursing home care to some individuals with very high-level care needs in their own homes;
- *National Continence Management Strategy*, funded from 1998 to 2005, to improve continence treatment and management; and
- *Assistance with Care and Housing for the Aged*, which connects vulnerable older people — many of whom live in inner

cities and have addictions and mental health problems and some of whom live on the street — to public housing and home care.

In addition, Australia has a *Commonwealth States & Territories Disability Agreement* to provide a range of services to young disabled persons that are not provided through the national home care system.

What Can Canada Learn from Australia?

The Australian health system has evolved differently from Canada's, where the national government has assumed more responsibility for non-acute home care services. Nonetheless, in moving forward on home care policy, it would be advantageous for Canada to assess the home care experiences down under. In Australia, both levels of government have acknowledged the importance of home care — and caregivers — to the health system and to Australians. They have agreed on the services that will come under the responsibility of each level of government, and have targeted populations at risk of not receiving adequate home care services. Beyond this, Australia has set an ambitious target for providing equal home care access to all. While Australia's system is not perfect, its policy-makers at the national and state levels continue to join forces to address — and attempt to overcome — home care challenges.

The effectiveness of home as a place for healthcare is a question of fact, not of faith.

— Laurence G. Thompson⁹¹

What We Know

What We Know About Home Care and Its Fit in the Continuum of Care

Australia has resolved to base its home care policies on the best evidence available. Canada has a considerable amount of information about home care — based on our own experience and that of other countries — but have we taken the next step of developing policy based on the research findings?

Two decades ago, our knowledge of home care was not extensive. Some studies emanating from the United States suggested that home care was not cost-effective, and the *Hospital and Home Care Study* undertaken in Saskatchewan in 1998 by the Health Services Utilization and Research Commission (HSURC) found that “seniors receiving preventive home care are more likely to die or lose their independence than seniors not receiving this service.”⁹² This finding flew in the face of the prevailing belief that home care is good quality care.⁹³ It also contrasted with the findings of a study by Hollander, which demonstrated that preventive home care was indeed cost-effective.

Hollander conducted a study of a natural experiment which occurred in British Columbia in the 1994 to 1995 period in which some health regions cut people from care who were at the lowest level of care need and were only receiving housecleaning services, and some regions did not make such cuts. He studied the overall costs to the health care system of people who were cut from service in two health regions to people who were not cut from service in two similar regions. In the year before the cuts the average annual cost per client for those who were cut from service was \$5,052 and the cost per client for the comparison group was \$4,535. For the third year after the cuts were made the comparative costs were \$11,903 and \$7,808, respectively, for a net difference of some \$3,500. Thus, on average, the people who were cut from care cost the



health care system some \$3,500 more in the third year after the cuts than people who were not cut from service.⁹⁴

It was evident that more research on home care was needed. We needed answers on many fronts: the quality of home care; its cost-effectiveness; under what circumstances, if any, it can best substitute for acute care; when it can best substitute for long-term care; and its effectiveness and cost-efficiency as a form of maintenance and prevention.

Enter the Health Transition Fund.

Health Transition Fund

Much of the information we have gleaned about home care comes from the Health Transition Fund (1997–2001), a joint effort among federal, provincial and territorial governments created in the 1997 federal budget. The Fund was intended to encourage and support evidence-based decision making in health care reform, and it sought to “test and evaluate new, better and more cost-effective ways of delivering health care services to Canadians.”⁹⁵ The Fund sponsored no less than 45 initiatives related to home care, which was identified as one of four priority areas. (The other three were pharmaceutical issues, primary health care and integrated service delivery.) These are some of the questions the home care initiatives sought to answer:

- Is home care quality care?
- Is it cost-effective, and if so, under what circumstances?
- Can greater access to it be achieved by underserved populations such as Aboriginal populations and mental health, dementia and palliative care patients?
- Can it adequately and cost-effectively serve the care needs of persons suffering from cancer, diabetes and heart failure?
- How can we best develop a comprehensive, standardized set of indicators about home care that will make possible comparisons of home care clients, programs and outcomes in various regions across Canada?

One of the initiatives, *The National Evaluation of the Cost-Effectiveness of Home Care*, consisted of 15 interrelated sub-studies that attempted to assess the differences in costs and quality between home care and various forms of institutional care. Six of the 15 sub-studies evaluated the cost-effectiveness of home care compared with residential long-term care, while the other nine evaluated the cost-effectiveness of home care as an alternative to acute care in institutions. Researchers examined the cost-effectiveness of specific services, such as home-based intravenous therapy and home care for low birth weight infants.

What the Health Transition Fund Initiatives Found

Home Care as an Alternative to Residential Care. Sub-study 1, *A Comparative Cost Analysis of Home Care and Residential Care Services*, which was carried out in British Columbia, found that savings of at least 50 percent could be obtained if home care replaced residential care for elderly clients who were stable in their type and level of care.

Other sub-studies found that home care is indeed less expensive, and not just because of the less expensive (or free) informal caregiver — although that is a contributing factor. Ostry points out that the cost savings

are due to three other factors. First, when acute care is delivered in the home rather than in the hospital, nurses are replaced by less expensive home-based workers. Second, the services can be rationed in the home setting. Third, in the home, various private fees can be charged for supplies and drugs.⁹⁶

Home Care as an Alternative to Acute Care. One initiative, Carelinks, which took place in the Simon Fraser Health Region in British Columbia, examined what happened when the region closed 30 beds and diverted some of the resultant savings to home care. The result: the region saved \$2 million, reinvested \$1 million into home care, and thus saved \$1 million annually, as long as the beds remain closed, with no detrimental effects experienced by patients.

In other initiatives, results were mixed. “A number of studies have been conducted to determine the cost and effectiveness of home care in connection with acute care hospitalization. Recent reviews of the literature have concluded that the results are mixed, with home care plus hospitalization being less costly than hospitalization alone in some diagnoses, but more costly in others.”⁹⁷

Three years of Alberta data were used in the *Costs of Acute Care and Home Care Services, Sub-study 9*, which found that in high-volume home care cases, the costs of hospital patients were higher for those who used home care than for those who did not.

Yet another initiative comparing the provision of intravenous therapy for cellulitis patients at home and in hospital found that acute care services could be provided more cost-effectively at home, with fewer complications and better outcomes. Also, *Evaluation of the Cost-Effectiveness of the Quick Response Program of Saskatoon District* found that a

community-based *Quick Response Program* could effectively redirect patients away from the emergency department to their home.

The Use of Geriatric Day Hospitals and Their Cost-Effectiveness. *Sub-study 10, Economic Evaluation of a Geriatric Day Hospital: Cost-Benefit Analysis Based on Functional Autonomy Changes*, found that for each dollar invested in care, \$2.14 of benefits were derived through improvement in functional status (a means of measuring the ability to perform daily tasks). Beyond the cost benefit to the system, clients reported improved cognitive function, greater opportunity for socialization, and increased feelings of well-being.

Home Care and Mental Health. *The Home-Based Program for Treatment of Acute Psychosis* reduced hospitalizations and hospital readmissions among those receiving home care services, although it achieved only modest savings.

Home Care for Home Care Clients Who Died. Overall, the 15-part study, *The National Evaluation of the Cost-effectiveness of Home Care*, found that costs were higher for clients who died while receiving home care than for those who died in facility-based care.

What Have We Learned from the Many Health Transition Fund Initiatives?

- Home care can provide quality care, but it is not appropriate for all patients/clients.
- Home care services may be a cost-effective substitute for facility-based long-term care, particularly for certain types of client care. According to these initiatives, overall, publicly funded health care costs represented between 50 and

75 percent of facility care. Costs for stable home care clients represented approximately 20 to 50 percent of facility care.

- Proportionally, savings are greater at the lower levels of care.
- Home and community care is also cost-effective in maintaining clients at an optimal level of functioning and preventing further deterioration in health status.
- Because hospital care costs more than home care provided by nurses and home support workers, more services and programs need to be designed to keep clients stable and supported at home — and out of the emergency department.
- It is difficult to keep patients/clients out of hospitals. Meeting this challenge will require many system-level changes. (See the section “Recommendations.”)
- Formal care costs are generally lower in home care, so savings are not attributed only to volunteer caregivers.

Primary Health Care Transition Fund

The six-year \$800-million *Primary Health Care Transition Fund* was created in 2000 to support provinces and territories and other stakeholders to develop and implement transitional primary health care renewal initiatives. This initiative had five objectives:

- to increase the proportion of the population that has access to primary health care organizations;
- to increase emphasis on health promotion, disease and injury prevention, and chronic disease management;
- to expand 24/7 access to essential services;
- to establish interdisciplinary primary health care teams of providers; and
- to facilitate coordination and integration with other health services.

Many initiatives had a partial home care focus — often as part of a strategy to improve chronic disease management, sometimes through telemonitoring and telehealth. One initiative had a primary focus on home care: the *National Partnership Project*. This initiative took place in Calgary and Halton/Peel, and involved partnering a home care case manager with a family physician team to assess patients’ needs. Almost 1,000 patients were included.⁹⁸ This proved to be a beneficial arrangement for all concerned: physicians felt more supported and found it easier to work with one case manager rather than several; both the case manager and physician worked side by side and developed greater respect for each other’s roles; and patients were better able to control their conditions and their health status generally improved.

Saskatchewan Home Care Review

The Saskatchewan Home Care Review, undertaken by Hollander at the request of that government, identified further information on the benefits of home care. The key findings from this 2006 report were positive:

...there seems to be a small, but reasonable, body of evidence to indicate that it may, in fact, be cost-effective to provide more basic (i.e., preventive and maintenance) home support services as a means of delaying institutionalization both for people with lower level care needs, and as a substitute for residential care services for people with higher levels of need for services. In addition, there seems to be some evidence to indicate that home care can function as a cost-effective alternative to residential care.

Another relevant finding was that there is some evidence to indicate that home care can indeed perform a substitution function for hospital services, through early discharge, with well designed programs. In addition, there is a growing body of evidence to indicate that there are a wide range of programs which can be put into place to reduce hospital admissions and/or readmissions....

... it appears it may be possible to think of home care not only as an important program in its own right, but also, as a key vehicle for increasing the efficiency and effectiveness of the broader health care system.⁹⁹

This report, along with those of the *Health Transition Fund* initiatives, constituted one more building block in the body of evidence in favour of a larger role for home care in the health system.

The Balance of Care Project in Ontario

The *Balance of Care* project takes its name from a methodology pioneered by Dr. David Challis and his colleagues at the University of Manchester in the United Kingdom. It is used to determine the most appropriate mix of institutional and community resources at the local level to meet the needs of an aging population. The Balance of Care method has six steps:

1. Identify “at risk” seniors — those currently occupying or deemed eligible for a long-term care bed.
2. Use assessment data to classify these at-risk seniors into multiple, relatively homogeneous groups (such as gender; need for help in performing activities of daily living and degree of help needed; presence and level of confusion; and presence of a carer).
3. Determine how many of the at-risk seniors fall into each group.
4. Select groups with more than 2.5 percent of the at-risk seniors and create a typical vignette for each group based on a real case.
5. Have case managers (or expert panels) review case vignettes, construct appropriate care packages and estimate the costs of these packages.
6. Determine which groups of at-risk seniors (and how many individuals in total) could be maintained in the community with less or comparable costs to the system (using facility care as a comparative base), and better or comparable outcomes for seniors and their carers.¹⁰⁰

The Canadian Institutes of Health Research (CIHR) Team in Community Care and Health Human Resources researchers under University of Toronto professor Paul Williams decided to adopt this methodology and apply it to an Ontario Local Health Integration Network (LHIN) setting. They posed the following research question: “What proportion of seniors on the long-term care waiting list can be safely and cost-effectively diverted to the community if given integrated packages of care?”

The researchers have been communicating the findings as the projects are completed. They suggest that deficiencies in performing instrumental activities of daily living (e.g. meal preparation, housekeeping, transportation, medication management) trigger placement on the wait list for long-term facility care. So far, the team has found that integrated community-based packages would be more cost-effective than long-term facility care placement for a significant proportion of seniors. The potential diversion rate varies between 37 and 53 percent, largely as a function of local differences in the use and availability of community services.

The Balance of Care team has reached the conclusion that home and community care can play a key role in two ways: maintaining the health, well-being and autonomy of individuals and caregivers; and moderating demand for costly acute and institutional care *provided* that home and community care is targeted, managed and integrated into the broader continuum of care. They note that supportive housing and “cluster care” (personal care services offered to a group of clients who live near each other) may allow for the more cost-effective use of resources.

In Ontario, the LHINs have been tasked with allocating resources among hospitals, long-term care, and home and community care, and with ensuring flexible and efficient delivery; therefore, this home-based information should be most useful to them.

The Continuing Care Research Project

The *Continuing Care Research Project*, undertaken by Hollander for Veterans Affairs Canada and the Government of Ontario, released its report in October 2008. The project included two studies. Study 1 involved an independent evaluation of the costs and outcomes of the Overseas Veterans and Veterans Independence Program initiative that was conducted in Halifax, Ottawa and Victoria. Study 2 examined the relative costs and outcomes of long-term home care, supportive housing and long-term facility care; it took place in Toronto and in the Peel, York and Durham areas.

Programs offered by Veterans Affairs Canada allow veterans to remain in their home as long as possible. They appear to be the only major ones still offered in this country that provide long-term maintenance and preventive care in the home.

The goals of the project were to obtain information on the relative success of the Overseas Veterans and Veterans Independence Program initiatives; to determine the cost-effectiveness of long-term home care, supportive housing and facility care; to examine the contributions of long-term home care and home support services with respect to the care of elderly persons; and to obtain information that could be used to contribute to the broader policy debate in Canada about health services for the elderly population.¹⁰¹

Both studies found that satisfaction levels were highest for home care clients, followed by clients in supportive housing and clients in facility care. Satisfaction levels across all three types of care were high overall for both clients and caregivers, yet home care costs were considerably less than those for facility care, while maintaining equivalent or better outcomes.

Recently, governments have tended to regard home care as post-acute medical care. But findings of this research project indicate that long-term care home services are valuable and cost-effective in that they either postpone people’s need for, or keep people out of, facilities and hospitals. The findings, along with those of other research projects conducted over the past decade, also point to the fact that it is time for long-term preventive and maintenance care home services to be back on the health policy agenda. Lastly, the project highlights the importance of the informal caregiver and the need to provide caregiver supports.

A 2008 study by Professor Markle-Reid and colleagues from McMaster University supports the assertion that modest amounts of home support services may reduce hospital services and long-term facility care.¹⁰²

Writes Hollander:

There is now a growing body of evidence that home care for persons with ongoing care needs can be a cost-effective intervention and can reduce demands on the institutional sector, thus increasing the overall efficiency of our health care system. In addition, there is also growing evidence that home support services are a central component of chronic home care services.

... the Canadian evidence to date is sufficiently robust that the burden of proof now falls to those who would argue that chronic, long-term home care is not cost-effective.¹⁰³

long-term home care and home support services, facility-based long-term care and supportive housing. Within such a system, substitutions of lower cost care for higher cost care can be made.

What Conclusions Can We Draw from the Research?

We can draw four major conclusions from this substantial body of research.

1. We have not fully utilized the evidence derived from government-sponsored studies in developing home care policy.
2. Long-term home care, for maintenance and prevention, particularly for those with disabilities and multiple chronic diseases, should be placed higher on the policy agenda.
3. Informal caregivers play a critical role in allowing people to remain in their community and maximize their independence. Support programs for these individuals could include greater financial support, recognition and more opportunities for respite care or day-away programs.
4. Home care is a vital part of the continuum of care. Its potential can best be realized within a broader, integrated system of continuing care that includes

... how these investments are actually made will make the difference between a successful policy and a failed policy.

— Marcus J. Hollander¹⁰⁴

Funding and Integrating

Grappling with Funding and Integrating Home Care

The evidence on home care effectiveness and desirability is available to policy-makers. What is preventing us from moving forward?

Canadians voice four concerns regarding the expansion of home care services: the cost of home care services; the fear of raising taxes to pay for them; the fear of applying co-payments or user fees because of uncertainty as to whether it is ethical to do so; and indecision about the services to which they should be applied. As a result, we have not fully addressed the issue of home care head-on.

England, on the other hand, is tackling the issue. (See box “Power to the People.”) *Securing Good Care for Older People*, a 2006 study by Sir Derek Wanless for the King’s Fund, a health and social care think-tank, expressly examined the home care funding question with a view to influencing long-term government spending to ensure good social care for the growing elderly population. The report is relevant to Canadians because it lays out a range of funding options and links the options to specific objectives: whether it is levelling the playing field to ensure equal access or improving access for certain populations

The English Example

The population of England is aging. In the next 20 years, the number of people aged 85 and over in England will increase by two-thirds, compared with a growth of 10 per cent in the population as a whole.¹⁰⁵



Power to the People

A number of countries are giving individuals who are entitled to publicly paid home care the choice of either money or service provision. Germany allows home care clients to receive either services or a cash payment worth about half the monetary value of the services option. In England, direct payments were introduced in 1997 for adults of working age, and in 2000 were extended to those aged 65 and over. Since April 2003, local councils have been obliged to make — not just offer — direct payments “where individuals consent to and are able to manage them, with or without assistance.” With an individual budget that clients can control themselves, they are able to choose their caregiver, pay for their own care and manage the desired services. It also allows them to choose a personal caregiver. The amount of money they receive is determined through a means test and consideration of their health and personal needs.” In England, the number of “adults and older people receiving direct payments per 100,000 of the population” has become a new performance indicator.⁽¹⁾

With direct payments, the responsibility of properly administering funds shifts to either the user or the family. One potential problem here is that they may find it difficult to ensure the quality and quantity of the services received.

Canada has some experience with direct payments, also called “individualized funding.” British Columbia’s *Choice in Supports for Independent Living* (CSIL) program, introduced in 1994, is an option for home care clients who wish to have greater control in managing their home support services. In 2002, Saskatchewan started offering individualized funding to those who wish to manage their support services. In 2005, Nova Scotia began to provide funds directly to clients with physical disabilities, permitting them to oversee the care and supports they require for daily living.⁽²⁾

In Ontario, the South East Local Health Integration Network (LHIN), which has the highest ratio of people aged 65 and over (16.7 percent) of all the LHINs, has begun to give recipients of home care services more options. After surveying beneficiaries of funds from the province’s *Aging at Home Strategy* on how to obtain the most benefit from the allocated money, the South East LHIN took their advice and created the *Seniors Managing Independent Living Easily* (SMILE) program. It is intended for seniors who are elderly, significantly frail and at risk of premature dependency and institutionalization, and is also intended to offer respite to their caregivers. SMILE gives seniors and their caregivers access to the home support services that they believe they most need;

Like all other developed countries, England is determined to provide quality home care to its aging population, and it is attempting to come up with a funding solution that not only is fair but also best meets the mounting need for publicly financed home care.

There are many ways to fund home care. Wanless considered five alternatives, which exist in other countries—and which all outranked the means test method that England currently uses. The alternatives are as follows:

1. Providing some form of universal entitlement to social care that is state-supported and not means-tested (e.g. free personal care), as currently exists in Scotland.
2. A social insurance model in which the state acts as an insurer and provides a package of care for people enrolled in the scheme, should they need care.
3. A partnership between state and individual where costs of care are shared for those needing care.
4. A limited liability model, which caps an individual’s liability for social care costs, either after a certain period or after they have made a specified financial outlay.
5. Savings-based models, which are often linked to pensions, where the state contributes to an earmarked savings pot that the individual can use to pay for care.¹⁰⁶

The Wanless Review favoured a partnership model, followed by free personal care, and then a limited liability model. It noted that they all differ in important ways:

1. The **partnership** model provides people with a free-of-charge minimum guaranteed amount of care. This is set in the model at 66 per cent of the total

benchmark care package but could be varied either up or down. Individuals could then make contributions matched by the state (up to a limit): in the model, every pound that people contribute is matched by a pound from the state until the benchmark care package is achieved (thereafter, extra private contributions are not matched). Those on low incomes would be supported in making additional contributions through the benefits system.

2. **Free personal care** provides a full package of personal care without charge.
3. A **limited liability** model is a hybrid, effectively a means-tested system for the first three or four years of care and then free personal care thereafter.¹⁰⁷

The report noted that no model was significantly better than the rest; they all have strengths and weaknesses. The choice of model depends largely on what one is trying to accomplish. Wanless expanded, “if protecting the poorest is paramount even if this means disadvantaging others, then systems with strong means-testing would score highly. If improving access to services for all people is paramount, then funding arrangements with universal entitlement approaches would rate well.”¹⁰⁸

Deciding on funding models for home care is difficult — and there are always trade-offs. Policy-makers must weigh the advantages and the disadvantages of the funding models in light of what they wish to accomplish and can afford.

One successful home care model in Quebec, PRISMA, has achieved great success *without* incurring extra costs.

without these services, the seniors might have to enter a long-term care facility. Services covered include meals, housekeeping, shopping, laundry, errands, seasonal outdoor chores and transportation.

Over the next few years, the SMILE program will be measured against agreed-upon indicators such as a reduced number of admissions to hospital and referrals to alternate levels of care. The United Kingdom experiment with the individual home care budget will also be closely monitored as policy-makers find out how direct payments may affect service quality and delivery costs.

Footnotes and Sources:

(1) U.K. Community Care, “It Pays to Be Direct.” Nov. 11, 2004. Retrieved Aug. 20, 2008, at: <http://www.communitycare.co.uk/Articles/2004/11/11/47062/it-pays-to-be-direct.html>.

(2) Canadian Home Care Association, **Portraits of Home Care in Canada 2008**, p. 145.

Sears, Nancy, “Redesigning Community Health: Where the Individual Needs of Seniors Drive the Supply of Services.” Presentation at Re-Imagining Health Services; Innovations in Community Health, Nov. 6–8, 2008, Vancouver, British Columbia.

Victorian Order of Nurses, “South East LHIN ‘smiles’ on VON: VON selected as regional management centre for innovative seniors program.” News release, Feb. 28, 2008.

PRISMA: High Value at No Extra Cost

The Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) is a Canadian model of integrated service delivery. Its aim is to improve the continuity of care and integrate services for frail older people and to provide them with the right balance of care for their needs in order to maximize their autonomy.

PRISMA is a multidisciplinary partnership between two academic research teams (Research Centre on Aging in Sherbrooke and Laval University’s Geriatric Research Team in Quebec City) and several health organizations, the Ministry of Health and Social Services, and five regional health and social services boards. This partnership of researchers, policy-makers, managers and

clinical practitioners undertakes relevant research and ensures that the results are quickly implemented in the field.

The PRISMA model of integrated service delivery is tailored to the publicly funded health care system. The model is unique in that it includes all public, private and volunteer organizations that provide care and services to frail seniors. Each organization keeps its own structure but agrees to participate in an umbrella system and to adapt its operations and resources to agreed-upon requirements. This model needs neither new infrastructure nor new financing mechanisms. Unlike other models, PRISMA is not run in parallel with the health care system but is embedded within it.

The key elements of PRISMA are coordination between decision makers; a single entry point; case management; individualized service plans; a single, common assessment tool; and a computerized clinical record, which all caregivers can access.¹⁰⁹

The success of PRISMA is evident first and most importantly in the success of its clients.

- Significantly fewer experienced functional declines, and this was true over both 12 months and 24 months.
- Their desire to move to a long-term care facility was also markedly reduced.
- Caregivers of PRISMA clients indicated that their burden was lightened.
- The number of visits to emergency departments was also lowered.¹¹⁰

Also, it has been adopted with success in many regions of Quebec and is highly regarded throughout Canada.

PRISMA supports Hollander's conclusions that expanding home care services need not be as expensive as some policy-makers fear.

Savings should be realized if home care is substituted appropriately (as happened in British Columbia, which proactively substituted home-based services for facility-based ones in the late 1980s to mid-1990s). It might take several years for these savings to be achieved, however. A body of research confirms the cost-effectiveness of home care, and this should help to give policy-makers the confidence to move forward. Confidence should also be bolstered by the fact that there are high costs associated with *not* moving forward on home care.

Informal caregivers are...silent victims in a silent system....they have inherited unfair burden and responsibility without enough support...

— Canada's Association for the Fifty-Plus (CARP)¹¹¹

The Givers of Care

Who Is Giving Home Care?

There are two elements to the home care relationship: the client/patient and the caregiver. Some caregivers are paid (formal), others are not (informal/family caregivers). The former can be regulated or unregulated — and interestingly, they can also be firefighters. (See box “Firefighters: The New Providers of Home Care.”)

Formal Caregivers

We know less about formal caregivers than informal caregivers. The 2003 *Canadian Home Care Human Resources Study* undertook an analysis to identify all home care provider organizations across Canada and the number of paid care providers within those organizations. Based on estimates from CIHI and Statistics Canada's Labour Force Surveys, the data are quantifiable but incomplete, and they may be duplicative (for example, social workers or nurses may be working in two settings). The study places the number of home support workers in 2001 at between 16,700 and 57,300. In comparison, the number of registered nurses in the home care sector for that year stands at 9,700 and licensed practical nurses at 2,400.¹¹² There are no reliable statistics for case managers, occupational, respiratory and speech therapists, dietitians, physicians and psychologists.¹¹³

Ontario has broken down home care visits in 2005 by profession, and the results give us insight into the nature of home care and the givers of care.



Firefighters—New Providers of Home Care

Susan Braedley, a York University doctoral candidate in sociology, has noted a recent trend: firefighters have rather surreptitiously become providers of home health care services, particularly since the late 1990s.

With 911 emergency call systems in place, she notes that firefighters and paramedics appear to be responding disproportionately to those who are poor, disabled, mentally ill, or elderly, and to those with chronic health care conditions. In most cases, the callers' health care needs are ongoing and complex yet remain inadequately addressed by more appropriate health care services, such as home care.

What are the implications of this trend?

- More and more health care needs are being addressed through short-term, emergency-style interventions.
- An intergovernmental shift has occurred. In Canada, health is a provincial responsibility, and fire services are generally provided by the municipal government (although they are regulated at the provincial level).
- The health care services that firefighters provide are not overseen or evaluated by the provincial Ministry of Health. In this, they are unlike paramedics, who are paid primarily through the Ministry of Health, which collects on the services they provide.
- No detailed intervention information is taken. We have no information on the effectiveness, costs or long-term implications of the health care provided by firefighters.
- This care takes place outside the health system and is invisible in terms of health policy.
- Firefighters are not adequately trained and prepared to respond to emergency health care calls of many kinds.
- Home care providers are generally female, firefighters generally male. Braedley notes that the rising proportion of health care work they undertake alters — and is at odds with — the perception of fire services as a purely public safety service and the hyper-masculine nature of the work.

This shift, with all its multifaceted implications, appears to be evidence that home care in Canada has been — and continues to be — developing by default rather than

Unregulated home support workers (personal support workers, home care aides, health care aides, personal care workers and attendants) play an active role in home care. Across the country, these unregulated health care workers deliver the bulk (70 to 80 percent) of home and community care services.¹¹⁴ (As can be seen from Chart 2, they delivered 67 per cent of services in Ontario in 2005.) They generally assist clients with bathing, dressing and other activities of daily living. These workers are predominantly female and are often new Canadians. Their training and language levels may or may not be adequate for the tasks they face in providing home or other forms of care, and this raises concerns for patient safety. The Canadian Nurses Association, in partnership with other professional associations, has organized a series of regional roundtables culminating in a national conference in March 2009 to discuss the roles of these critical health workers in the system.

Concerns have also been raised about the safety of the personal support workers and the labour conditions under which they work. Health and safety concerns include back strain due to physical lifting and transferring of clients; stress, fatigue and burnout; emotional costs of working with palliative, terminally ill persons and clients with dementia or Alzheimer's disease; and fear of infection, isolation, safety hazards in the home and physical abuse (of workers) by clients and family.

The compensation levels of those providing home support services are generally lower than in other health care settings. At the Ontario Health Coalition's Home Care Hearings in 2008, personal support workers' chief complaints were job security, low wages, poor or no benefits, and lack of sufficient compensation for travel time and mileage.¹¹⁵ The lack of guaranteed hours and the high

costs of formal training, especially in private schools, ranked as other deterrents.¹¹⁶

Despite these negative aspects, the workers emphasized how much they love their work.

Those who provide home care cite some advantages. Professionals are able to work more independently and often to the full scope of practice, and both professionals and non-professionals derive satisfaction from providing care on a personal basis. However, formal caregivers often lack team support from other health professionals and colleagues, work in isolation and in a home setting that is often unpredictable, and endure considerable physical strain.¹¹⁷

Not surprisingly, human resources shortages in the home care sector are chronic and well reported. Both recruitment and retention are problems.

Differences Across the Country

Home care is delivered by public, private not-for-profit and private for-profit agencies in Canada. Differences exist among provinces and territories in the delivery of home care. In some regions, home care workers are public employees (Saskatchewan, Yukon, the Northwest Territories and Nunavut), while in others a mixture exists. Ontario differs in that none of its home care providers are public employees. (See box “Ontario’s Competitive Bidding Model and Its Implications for Formal Home Care Providers.”)

The issue of competitive bidding also raises the question of the advantages and disadvantages of public, for-profit and not-for-profit delivery of services. Opinions differ as to whether one is preferable to the others in terms of recruiting and retaining home care providers. The balance favours public delivery.

design, and that it remains on the margins rather than in the mainstream of the health system.

Source:

Braedley, Susan, “Accidental Care: Masculinity and Neoliberalism at Work,” in Braedley and Luxton (eds.), **Penetrating Neoliberalism: Power, Social Relations, Contradictions**. Montreal/Kingston: McGill Queens Press, forthcoming.

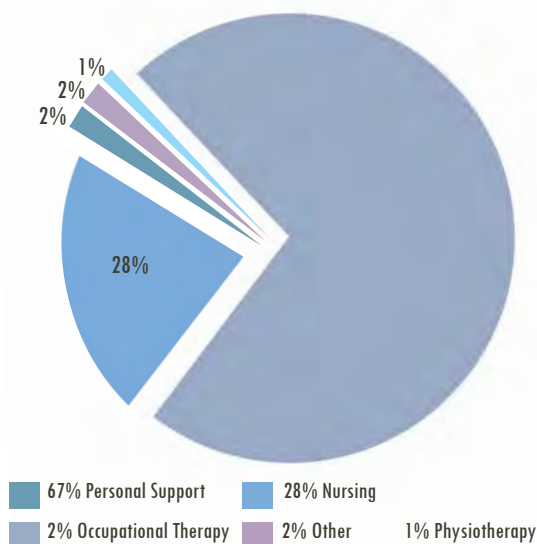
In 2007, a decision by the Hamilton Niagara Haldimand Brant Community Care Access Centre to “disqualify” two non-profit providers — St. Joseph’s Health Centre and the Victorian Order of Nurses — following a competitive bidding process provoked public outrage. Together, the two providers had almost two centuries of service in the Hamilton community.¹¹⁸ Sparked by the outcry, the Minister of Health and Long-Term Care ordered a review of the bidding process in January 2008. This was the second time the Ontario government had imposed a province-wide moratorium on competitive bidding in home care (the first was between 2004 and 2007). The moratorium was quietly removed in December 2008.

Health Human Resources Challenges in Home Care

The home care sector suffers from human resources shortages. Findings from a 2007 case study of 835 Ontario home care workers indicated that a competitive bidding approach may decrease levels of job satisfaction and lead to higher attrition levels among home care workers.¹¹⁹ When the employer loses a contract, providers lose their job, may be rehired by the new provider, or may choose to leave the home care sector for more stable employment.

The 2005 report *Satisfied Workers, Retained Workers, Effects of Work and Work Environment on Homecare Workers’ Job Satisfaction, Stress, Physical Health, and*

Chart 2: Home Care Visits in Ontario by Service Type, 2005



Source: The Change Foundation. Facing the Facts: Homecare in Ontario, User Profile & Areas for Improvement. N.d. http://www.changefoundation.ca/docs/Facing-Facts_HomeCareOnt_3.pdf. Data source is Home Care Database, Ontario Ministry of Health and Long-Term Care (Finance and Information Management Branch) Reproduced with permission.

Retention “shows that there are differences in working conditions between non-profit and for-profit agencies in terms of pay, benefits, and continuity of hours...”¹²⁰

The 2003 *Canadian Home Care Human Resources Study* reported the following:

- those working for government or regional health authorities received the highest rate of pay;
- registered nurses and registered practical nurses typically received higher rates of pay in not-for-profit agencies;
- physiotherapists, occupational therapists, social workers and home support workers received higher rates in for-profit agencies;
- tenure was longest for government or regional health authority employees and for unionized employees;
- full-time workers stayed longest, casual workers the shortest amount of time; and
- there was greater turnover in for-profit organizations than in public or not-for-profit organizations.¹²¹

The 2008 Report of the Ontario Health Coalition’s Home Care Hearings, *Home Care: Change We Need*, points out that for-profit organizations have few options for making a profit in home care, and can usually do so through six possible avenues:

- selecting easier-to-serve clients;
- avoiding markets with low volumes or other high-service costs, such as travel to rural and remote areas;
- paying lower wages to workers, usually achieved through keeping unions out;
- offering only part-time work, thereby avoiding payment of benefits to workers;
- using lower-skilled workers; and
- not providing training for workers.¹²²

The authors underscore that, in home care, “where the majority of expenses are labour costs, lowering costs is usually at the expense of workers and outcomes for clients.”¹²³

Given that the home care sector requires a stable and sufficient number of staff — both regulated and unregulated — it is imperative to address the human resources challenges facing the sector. The authors of the report *Satisfied Workers, Retained Workers* make the following suggestions:

Sufficient government funding to provide services, avoiding continuous changes in the work environment, and making rational restructuring decisions based on input from all stakeholders can contribute to healthier workplaces and healthy workers. In addition, providing resources in homecare to provide more permanent jobs with wages and benefits that match the acute and long-term care system will help to improve retention and recruitment in the homecare sector.¹²⁴

Some provinces are moving away from this discussion, instead focusing on integrated approaches to human resources and

meeting the challenges of compensation differences between the acute care sector and home care. They are also trying to address the need for more education and skill development for home care workers due to the increasing complexity of home care clients.

Informal Caregivers

The home care system could not exist without the large volunteer workforce that supports it. How large is this workforce? The 2007 *Health Care in Canada Survey* (Pollara) indicates that 23 percent of Canadians had provided care for a family or friend with a serious health problem within the past year,¹²⁵ while the Health Council of Canada says the proportion is 26 percent.¹²⁶ Informal caregivers are the backbone of the health and long-term care system in Canada.

Although previous studies and surveys have indicated that the burden of care has fallen mostly on the shoulders of females, the Pollara survey indicates otherwise. Its findings point to a more equal division between males and females. Pollara notes that, in 2007, 21 percent of men and 26 percent of women had personally cared for a family member or friend with a serious health problem in the past 12 months.¹²⁷

Research undertaken on First Nations and Inuit caregivers indicates that they have been and are still providing a great deal of care each week. About one in three caregivers supports two or more persons needing care.¹²⁸

The Effects of Caregiving on Caregivers

The increased demand for the provision of care in the home is exacting an economic

Ontario's Competitive Bidding Model and Its Implications for Formal Home Care Providers

In Ontario, service delivery has changed from a public and not-for-profit model to an open competitive one where for-profit and not-for-profit agencies may compete for contracts to deliver home care services.¹⁹³ This change has grabbed the attention of other governments and has sparked debate in many quarters, including unions, home care employees, home care clients and organizations delivering home care services. The process has both critics and proponents.

The critics of competitive bidding believe that it:

- places financial considerations ahead of quality patient care;
- favours for-profit home care organizations over not-for-profit ones, as the bidding process is costly and larger organizations can afford to sustain losses over the short term to gain a foothold in the system;
- leads to a growing consolidation of organizations offering home care services rather than a proliferation of them, thereby reducing competition;
- destabilizes the home care sector;
- bodes poorly for continuity of care and integrated care;
- drives down the pay of home care providers;
- contributes to the high turnover rates of formal home care providers;
- is a factor in home care providers leaving the home care sector; and
- does not provide savings to the public purse.

The proponents of competitive bidding believe that it:

- drives quality;
- leads to consolidation of providers that may reduce variance in standards;
- delivers cost-efficient care, and
- promotes innovative practices.

Source:

Kushner, Carol, Patricia Baranek and Marion Dewar, *Home Care: Change We Need*. Report on the Ontario Health Coalition's Home Care Hearings, Nov. 17, 2008.

and emotional toll on Canadians caregivers. Evidence is also mounting that the health of caregivers, particularly those caring for loved ones with dementia, is suffering as a result of the burden they bear.¹²⁹

Among home care clients with informal caregivers, clients with moderate to severe cognitive impairment were three times more likely to have caregivers who expressed symptoms of caregiver burden than those who were cognitively intact.¹³⁰

The Pollara survey found that, in 2007, 41 percent of caregivers had to use personal savings to survive; 22 percent took off one or more months of work, whether all at once or over the course of the year to provide care; 11 percent had to quit work to provide care; 9 percent accessed other benefits from their employer; and 7 percent took advantage of the Employment Insurance Compassionate Care Benefit.¹³¹

The University of Alberta is conducting an ongoing research program about seniors: *Hidden Costs/Invisible Contributions*. It is so named because it aims to make explicit the hidden costs of care and the contributions of older adults and adults with chronic illness/disability. It is examining working Canadians over the age of 45 who are providing care to seniors, and is finding that these caregivers are not only sacrificing income but also jeopardizing their future pension benefits.

The researchers divide their findings on the costs to caregivers into three categories: employment-related, out-of-pocket, and direct labour. The researchers find that the average estimated lost earnings for all Canadians due to caregiving are between \$3,732 and \$16,665. The estimated public and private pension benefit losses amount to \$92,696. Caregivers incur estimated additional out-of-pocket expenditures of \$19,525. (Funds are expressed in American currency since the project is international in scope.) The researchers estimate that the work undertaken by some 2.1 million Canadian caregivers to seniors is equivalent to that of 275,509 full-time employees. They

also estimate the aggregate economic value of this work to be \$5.1 to \$5.7 billion.¹³² Clearly, this is an enormous contribution.

Although society benefits through family caregiving, also it comes at a cost. Caregiving costs the economy in terms of lost productivity, job vacancies and increased training requirements when employees must be replaced. As the labour market continues to tighten, this issue will become increasingly critical.

A major study on wait times recognizes that caregivers who remain in the workforce are paying a price supporting loved ones awaiting medical appointments and procedures, and that this in turn has an adverse effect on the Canadian economy.¹³³ The study measured caregiver costs attributed to “reduced economic activity as a result of caregivers giving up work to care for family members or relatives...the direct loss in production from these people no longer producing goods and services as well as the broader reduction in economic activity resulting from reduced incomes and lower spending.”¹³⁴

Its findings include:

- For total joint replacement, caregiver costs exceed the costs generated by the patients (due to the number of patients who require the assistance of a caregiver and the relative youth of the caregivers increasing the likelihood that they had to withdraw from the labour force).
- The distribution of costs between patient and caregiver is nearly equal for cataract surgery (the proportion of patients requiring a caregiver is close to the proportion of patients who need to discontinue their regular activities, although 66 percent of these caregivers are more than 65 years old).

- For coronary artery bypass graft surgery, the high proportion of patients who must discontinue their regular activities leads to patient costs exceeding caregiver costs by a margin of nearly 3 to 1. The fact that nearly half the caregivers for these patients are over age 65 reduces the level of caregiver costs.¹³⁵

Caregiving affects not just the financial status of caregivers but also their emotional and physical health. A project undertaken by the Research on Aging Policies and Practice (RAPP) at the University of Alberta examined the effects of caregiving on caregivers. They found that the cost is exacted somewhat differently on males and females. The researchers used Statistics Canada's 2002 *General Social Survey* on aging and social support to draw a sub-sample of people aged 45 and over who had provided assistance in the last year to an adult aged 65 or older with long-term health problems. Though the numbers do not reflect the full scope of caregiving in Canada, RAPP's summary of findings highlights some key differences between male and female caregivers:¹³⁶

- Male and female caregivers were similar in age, with nearly half aged 59 to 74, although slightly more women than men were 75 years of age or older. Caregivers mirrored the general population regarding place of residence, with three-quarters living in urban areas and one-quarter in rural.
- More men than women caregivers were married, had children under 15, and were employed full time.
- More women than men caregivers worked part time or were not employed, which the researchers suggest might be due to their caregiving demands.
- Caring responsibilities differed slightly between men and women caregivers, with more men having cared for two years or more, for two or more persons, and for a parent (in-law) or non-kin.
- More women than men reported negative physical, social and emotional consequences of caring. Women were more likely to report that their physical health was affected, that their sleeping patterns had changed, that they felt stressed because of their care responsibilities, and that they had changed their social activities and holiday plans. More women than men reported feeling burdened, angry, wished others would take over their caregiving duties or help them more. That said, both reported equally the positive benefits of providing care.
- Caregiving affected employment, especially for women. More women (one in seven) than men (one in ten) caregivers reduced their hours of work or changed their work patterns, and thereby reduced their incomes.
- More than one-third of all caregivers, regardless of gender, incurred extra out-of-pocket expenses.
- More women caregivers incurred economic costs. Nearly one-and-a-half times more women than men reported reduced income (9.8 percent female versus 6.6 percent male).

The differences between the RAPP survey — which indicates that 2 percent of female caregivers and a negligible number of male caregivers left their jobs to provide care — and the Pollara survey — which indicates that 10 percent of caregivers left their job — might be attributable to these factors:

- The RAPP study is based on 2002 data and the Pollara on 2007 data;
- The samples are different: between 2002 and 2007, the Canadian population aged and the number of persons requiring care increased, and

the caregivers, who are also older, are less willing or able to manage both their caregiving and work duties.

Statistics Canada's results of the 2007 *General Social Survey on Caregiving* indicate that, between 2002 and 2007:

- the number of caregivers increased, from 2 million to 2.7 million;
- the proportion of female caregivers increased by 4 percent to 22 percent; the proportion of male caregivers remained the same, at 19 percent;
- nearly 70 percent of care was provided by close family members;
- nearly 40 percent of female caregivers and less than 20 percent of male caregivers provided personal care, which includes bathing and dressing;
- approximately 60 percent of women and 30 percent of their male counterparts performed regular tasks inside the house, such as meal preparation, cleaning or laundry;
- male caregivers were more likely to provide assistance with tasks outside the house, such as house maintenance or outdoor work, but the women who did were more likely than men to do so at least once a week;
- both genders (8 out of 10) assisted with transportation;
- caregivers were less likely to take on medically related tasks than other types of tasks. Of those who did, women (25 percent) were more likely to do so than men (16 percent);
- women (42 percent) were more likely to assist with care management (scheduling appointments) than men (33 percent);
- the majority of caregivers said they were coping with their caregiving responsibilities. More than half said they were coping very well; more than 40 percent were managing fairly well; less

than 5 percent indicated that they were doing not very well or not well at all.¹³⁷

The survey also revealed these statistics:

- In 2007, nearly 43 percent of caregivers were between the ages of 45 and 54, a time of life when many Canadians still have children living at home. About three in four caregivers were married or living common-law. More than half of the caregivers (57 percent) were employed.
- In 2007, family and friends between the ages of 45 and 64 years had been providing care for an average of 5.4 years. Caregivers aged 65+ had given assistance for an average of 6.5 years. Approximately 10 percent of all caregivers aged 45 and over had been providing care for at least 13 years; the majority of these were married women, and half of them were employed.

Statistics Canada's results of the 2007 *General Social Survey on Caregiving* are limited in that they reflect only data about caregivers between the ages of 45 and 64. The 2007 survey affirms and elaborates upon the findings of the earlier surveys that caregiving is common, that females are more affected and provide a deeper level of care, and that caregivers have responsibilities beyond providing care. The most interesting difference between the 2007 survey and the earlier ones is that the majority of caregivers in the 2007 one indicate that they are coping quite well, perhaps because of the relatively youthful age group surveyed and the exclusion of the majority of caregivers — those aged 65 and over.

How Are We Recognizing the Contribution of the Caregiver?

Those caregivers who provide care to a dependant in their home — a person who is dependent due to physical or mental disability or because of their advanced age and who has an income of less than \$17,000 — can claim a deduction of \$4,019 on their 2007 federal income tax form. The federal government also offers tax relief in the form of the medical expense tax credit, the disability tax credit, and the attendant care expenses deduction. Certain caregivers may also be eligible for the *Compassionate Care Benefit*. Janet Fast, a professor in the Department of Human Ecology at the University of Alberta, notes that, “while collectively these tax credits may amount to as much as \$10,000, few caregivers are, in fact, eligible for anywhere near this amount. As a general principle, the credits are least useful to caregivers who most need financial assistance.”¹³⁸

The Compassionate Care Benefit

This benefit was the federal government’s response to public pressure seeking recognition and economic support for informal caregivers. Data indicate that the unpaid care provided by family and friends would cost the country’s health system approximately \$6 billion annually if delivered by a paid workforce.

The *Compassionate Care Benefit* was introduced in January 2004. It offers eligible caregivers leave of up to eight weeks and financial help that amounts to 58 per cent of a caregiver’s salary for a maximum of six weeks during that time. It is provided through the Employment Insurance system for those care providers who are already in the workforce and are eligible

for unemployment insurance. As originally introduced, the benefit was limited in that it was intended only for caregivers who would be providing care or support for a family member (spouse, child, parent or common-law partner) with a significant risk of death within six months. In June 2006, the government redefined “family” so that any person designated by the dying person as family, such as family members, friends or neighbours, could receive the benefit.

Is the Compassionate Care Benefit Adequate?

A decreasing number of Canadians are eligible for employment insurance. In the 1970s, 85 percent of Canadians paid into this program, compared to approximately 55 percent today. Caregivers who are self-employed, part-time or casual, retired, or not in the formal workforce are ineligible for this benefit. This is significant in that non-standard employment continues to grow, suggesting that fewer workers will be eligible to receive the *Compassionate Care Benefit*. Professor Fast notes that marginalized workers — meaning persons without steady employment, those who work reduced hours, who have been in and out of the workforce, or who are homemakers or living on a pension — are likely to be first within a care receiver’s network to be relied upon for end-of-life care. Ironically, they may be in greater need of the *Compassionate Care Benefit* than those who have more regular work.¹³⁹

The Compassionate Care Benefit is intended only for those who care for a person who is expected to die within six months. This excludes a majority of caregivers: those caring for individuals who are suddenly incapacitated due to an accident, heart attack or stroke, who are chronically ill, disabled or mentally

ill, or who suffer from degenerative brain diseases such as Alzheimer's or other forms of dementia. The Alzheimer Society of Canada notes on its website that, in 2008, an estimated 450,000 Canadians over 65 had Alzheimer's or a related dementia. Half of the 300,000 diagnosed with Alzheimer's live in the community. It is unlikely that their caregivers would be eligible to receive the Compassionate Care Benefit.¹⁴⁰

It is often hard to predict when someone is within six months of death. Obtaining the required certificate from a physician or other health care provider therefore is often difficult.

Six weeks of benefits and eight weeks of leave are not enough. A review of caregivers investigating their desire and/or ability to access the Compassionate Care Benefit found that the vast majority of caregivers, including end-of-life caregivers, provided care to the patient for more than a year.¹⁴¹

Many caregivers are frustrated by the inefficiencies built into the current application process. At a time of great stress, caregivers might decide not to take the time away from caring for the dying person to fill out an application, obtain a statement from their employer and a physician's statement that death is imminent.

Current eligibility criteria, in particular, render a majority of caregivers — even end-of-life caregivers — ineligible for the program.¹⁴² It is therefore perhaps not surprising that the Pollara 2007 survey found that 90 percent of caregivers either did not apply for or did not receive the benefit.

Other Supports for Caregivers

There are other ways to support caregivers: providing information on care, volunteer services (such as Meals on Wheels), formal in-home services (paid for publicly or privately), supportive housing, respite care (offered either in the home or in long-term care facilities) and day-away programs. In Canada, respite care and day-away programs are often provided at the local level, so it is difficult to know how many caregivers are getting this assistance, and whether it is sufficient.¹⁴³ (See box "Some Leading Support Practices from the Netherlands and Denmark.")

Recognizing that caregivers are often parachuted into their role with little or no preparation, some organizations have produced publications to help caregivers in their roles as patient caregivers and advocates.

- The Victorian Order of Nurses (VON) developed *The Caregiver Best Practice Manual* and is expanding its caregiver web portal (www.caregiver-connect.ca) with the intention of making it a "one-stop-shopping" resource for caregivers.
- The Canadian Hospice Palliative Care Association and the GlaxoSmithKline Foundation produced the booklet *Influencing Change: A Patient and Caregiver Advocacy Guide*.
- The Canadian Hospice Palliative Care Association produced a comprehensive guide for caregivers, *Training Manual for Home Support Workers*, which can be purchased directly from them.
- The Canadian Hospice Palliative Care Association (www.chpca.ca) offers resources for caregivers and health professionals, some of which are free (*A Caregiver's Guide: A Handbook of End of Life Care* is available in many languages,

including those of First Nations and Inuit peoples).

- *The Family Caregiver*, a resource magazine, also has a website: www.thefamilycaregiver.com.
- The VON is expanding a *Neighbours Helping Neighbours* program to train volunteers to develop the skills they need to help others. Volunteers receive training in subjects such as family dynamics, the aging process and pain management.¹⁴⁴
- The Canadian Caregiver Coalition represents and promotes “the voice, needs and interests of family caregivers with all levels of government, and the community through: advocacy and leadership; research and education; and information, communication and resource development.”¹⁴⁵

In Ontario, various organizations are coordinating care for the caregivers through the newly established *Family Caregiver Connections Project*. The project is being funded by the province through the Central Local Health Integration Network as part of Ontario’s Aging at Home Strategy. The project’s aim is outreach and prevention, encouraging caregivers to obtain respite.

In Canada, the federal government does not play an overt role in recognizing, supporting and educating carers. There is no national caregivers day, no national caregivers summit. We have one national organization dedicated to caregivers: the Canadian Caregivers Coalition. It offers information to support caregivers, and its website lists the three provinces that have caregiver associations (British Columbia, Alberta and Nova Scotia) and the disease-specific organizations that offer caregiver support. Its website is the Canadian equivalent of Carers UK (www.carersuk.org) and Carers Australia (www.carersaustralia.com.au). This latter website directs the visitor to a 1-800

Some Leading Support Practices from the Netherlands and Denmark

The Netherlands has:

- *old people’s advisors*, trained volunteers and professionals who give unbiased advice to seniors. The advisors offer advice on social/community care, health, options, housing, finances, etc.;
- *Alzheimer’s cafés*, which Alzheimer’s patients and their families can attend together to meet others in a similar situation, learn about the disease and its progression, socialize, eat and drink. The driving thought behind the cafés is to preserve as normal a life as possible, for as long as possible. The cafés give a social face to Alzheimer’s disease, and offer those suffering in isolation opportunities to come together, and also offer a place for bereaved persons to come;
- *local preventive health care centres* for old people;
- *meeting centres in the community*, where individuals and their carers can socialize and obtain advice on an informal basis; and
- *care farms*, where people, old and young (with autism, Alzheimer’s, learning disabilities, or mental illness, or who have been formerly incarcerated) can assist in rural work. There has been a rapid expansion of these farms over the past decade, and people prefer them to day centres.

Denmark offers green dementia care, which involves getting carers and clients out into nature three times a week. Nature spurs memories, gives those with dementia some freedom, and puts them on a more equal footing with their carer. Both carers and clients enjoy these outings and find that they strengthen their relationship.

Sources:

- Nies, Henk, “International Perspectives.” Presentation at the Canadian Research Network for Care in the Community conference *Look Globally, Act Locally: Integrating Care in the Community for Vulnerable Populations*, Toronto, Ontario, Oct. 20, 2008.
- Swane, Christine, “As Good as It Gets — in Denmark: From Preventive Home Visits to Reminiscence and Nature in Dementia Care.” Presentation at the *Re-Imagining Health Services: Innovations in Community Health Conference*, Vancouver, British Columbia, Nov. 7, 2008.

telephone number to speak to someone at the visitor’s closest caregiver organization. Likewise, Carers NewZealand (www.carers.net.nz) represents the interests of its country’s caregivers, focusing on supporting them, informing them of web-

based tools to help them in their caring responsibilities, and advising them of progressive legislation regarding caregivers in other countries and of developments that affect caregivers in their own country.

In Canada, the sources of information for carers appear to be less clear and more difficult to determine than in the United Kingdom, Australia and New Zealand. We rely on disease-specific and other organizations (like those listed above), some of which might not be known to the many caregivers across the country.

How We Compare Internationally in Our Support for Caregivers

For the purposes of comparison, we will look at the United Kingdom and Australia.

The UK has introduced a state pension for caregivers who earn little or no income. Caregivers are entitled to a Carers Allowance, other benefits and help with housing costs. New legislation has been created for the 3 million caregivers in the United Kingdom who combine working and caregiving responsibilities. Since April 2007, caregivers have a right to request changes to their working patterns to better manage their caring. Employees are entitled to time off in the event of an emergency involving dependants and are permitted leave each year to care for a child under the age of 5 or a disabled child under the age of 18.¹⁴⁶ Australia offers educational, moral and financial support plus respite relief to caregivers. Commonwealth Carer Resource Centres are located in each capital city. Eligible caregivers can receive up to 63 days of respite care. The Carer Allowance (non-income tested and not taxable) is paid to people who care for a relative or a friend at home who is assessed as requiring a fairly

high level of care. An income-tested Carer Payment provides income support (similar to a pension) to people caring for someone who is in need of constant personal care or supervision at home for six months or more — including frail older people.

Australia also has these initiatives in place:

- a National Dementia Behaviour Advisory Service for carers and respite care staff that can be accessed through a Dementia Helpline;
- a Carer Education and Workplace Training Project, which offers training and education for caregivers and paid workers; and
- Psychogeriatric Care Units, which are generally attached to large public hospitals. These units offer clinical services as well as advice to caregivers and staff of residential facilities on dealing with difficult behaviours associated with dementia.

The major difference between Australia and Canada is that, in Australia, these programs and services are national, government-driven and sanctioned. Canada offers similar services, but does so through disease-specific and charitable organizations, such as the Alzheimer's Society or the VON. Canada could do more to boost awareness of and access to educational support; provide advice; moral support; financial support; workplace support; and flexibility in pensions. Canada could also show more recognition of caregivers on a national basis.

Professor Fast notes that Canada lags behind other industrialized countries in its patchwork of caregiving policies. Researchers have noted, "The danger is not that families will abandon their ill relatives but that the health care system will abandon its caregivers."¹⁴⁷

In order to develop an efficient, effective and integrated system of home care that has explicit recognition of Canadian values, many issues must be addressed.

— Malcolm Anderson and Karen Parent¹⁴⁸

These issues include growing pressures on limited human resources, insufficient funding, reductions in home supports, the shifting of responsibility or care to the family caregivers (exceeding their capacity to cope), and concerns surrounding leadership and direction for home care policy and planning, both provincially/territorially and federally.

— Canadian Mental Health Association¹⁴⁹

Challenges as Yet Unmet

There is no shortage of challenges relating to the provision of home care and to addressing the needs of caregivers in Canada. This much is clear upon our analysis of home care, international comparators, home care research, and caregiver issues.

A 1999 report by the Association of Fifty-Plus, formerly the Canadian Association of Retired Persons (CARP), identified the following issues as being of paramount importance:

- lack of leadership (no coherent strategy for developing home care);
- human resources;
- inadequate funding;
- caregiver burden;
- pressures on the voluntary sector;
- diminished access and inequities for accessing home care (policies have decreased the eligibility criteria for home care);
- the medicalization of home care;
- increased privatization;
- reduction in home support;
- variation in services;
- lack of knowledge and awareness; and
- lack of research.

Nearly 10 years later, these issues have not been addressed, except for the latter two points. Meanwhile, the need for home care is growing, not abating.



A Summary of Challenges

The following summary highlights some of the most pressing home care challenges.

Lack of federal leadership. Though various provincial/territorial goals and standards have been established, none have been set at the national level for long-term home care.

Lack of integration. Many jurisdictions still need to focus on seamlessly integrating home care within the health care sector. The Health Council of Canada noted this deficiency in 2008:

Although federal, provincial and territorial governments have vision statements to guide their renewal efforts in both primary health care and home care, few governments have set targets or have implemented strategies for measuring, monitoring and reporting on progress.... And few jurisdictions report an integrated approach to home care, suggesting that they have yet to view home care as a seamless extension of the health care system.¹⁵⁰

Most governments have met commitments made in 2004 to provide two weeks of publicly funded home care services for post-acute care and palliative care patients or individuals who are in acute mental stress. The Health Council of Canada notes that there is room for progress in light of the fact that in 2005, 2–5 percent of Canadians used home care services while 3–4 percent of seniors said they needed home care services they did not receive.¹⁵¹

Continued emphasis on short-term, post-acute home care rather than preventive long-term home care. Governments tend to concentrate on one form of home care at the expense of another. As Hollander notes:

Current policies which favour the provision of publicly funded home care services to people discharged from hospitals have the effect of making home support services less available to those who need support over a longer period of time. The above, and initiatives to disenfranchise individuals by cutting people who need lower levels of care from service, tend to shift fiscal responsibility for the financing of needed care services from the state to the individual.¹⁵²

Inadequate data collection. In 2001, CIHI created the *Home Care Reporting System* to provide comparable data on publicly funded home care to support policy-makers, health planners and front-line providers. The system covers the continuum of care from acute, rehabilitation and long-term to end-of-life care delivered through home care programs. In February 2007, Yukon became the first jurisdiction to submit data to CIHI's *Home Care Reporting System*. As more jurisdictions participate, policy-makers will be able to track progress and monitor trends over time and make comparisons of outcomes and resources.¹⁵³ We are making progress, although gaps remain. We have little information on human resources and turnover rates, use of respite care, and wait times for services for children. The latter issue is critical; often, children cannot receive publicly funded home care services until after they have received a diagnosis.

Palliative care. Statistics Canada recently reported an increase in death rates, reflecting our aging population: 230,132 Canadians died in 2005, up 1.6 percent from 2004.¹⁵⁴ (See box "Ontario's End of Life Strategy.") Most die in hospital because of a shortage of palliative care physicians and nurses, as well as a lack of 24/7 case management support.¹⁵⁵ CIHI noted in 2007 that "variation in care suggests that an integrated, systematic approach to end-of-life care does not yet exist."¹⁵⁶

Health human resources. Canada is experiencing the global health human resources shortage. Most provinces and territories have a shortage of nurses and a range of other home and community care workers, a situation that is more pronounced in rural and remote areas and especially problematic when seeking staff with specialized skills for specific client populations (e.g. mental health, pediatrics). In addition to recruitment difficulties, retention challenges also confront the sector.¹⁵⁷

Other resources. Effective home care requires not only human resources but also the products and commodities necessary to deliver care effectively (e.g. home oxygen machines) and broader aspects of community infrastructure (e.g. spaces for day programs for elderly clients with dementia). These elements are sometimes lacking, particularly in smaller, more rural and remote communities.

Lack of uniformity across the country. Substantial variations exist both among and within provinces and territories. These relate to co-payments and user fees, the basket of services offered under the home care umbrella, public coverage of costs for drugs, supplies and equipment; and the limits set on the amount of home care a client may receive.

Lack of portability. Services and benefits generally do not travel with the home care client. Residency requirements differ, which makes it complicated to move family members closer to willing caregivers.

Difficulties in delivering home care services in rural and remote communities. These persist and are often difficult to overcome. The result is unnecessary use of acute-care facilities.

Ontario's End-of-Life Care Strategy

This care is intended for individuals at the end of life (EOL) who are usually older, living with serious chronic illness, disability and multiple co-morbidities, and who often receive fragmented and costly care. In October 2005, the Ontario Ministry of Health and Long-Term Care, with support from the 2004 Health Accord, developed the three-year End-of-Life Care Strategy to improve care for these individuals.

The Strategy's main objectives were threefold: to shift care of the dying from acute care to alternate settings; to improve client-centred and interdisciplinary service delivery capacity in the community; and to improve access, coordination and consistency of services and supports across the province.⁽¹⁾

The Ministry's Home Care and Community Support Branch funded a research study to determine whether the strategy had been successful in meeting its objectives. It found the following:

- In its first year, Ontario served 3,500 more EOL clients and provided more care per client than in the previous year.⁽²⁾
- The EOL care networks that were developed have improved collaboration among providers, resulting in improved coordination, communication and consistency of care.⁽³⁾
- Clients and their families are receiving more help to navigate the health care system, and more of their preferences are being met.⁽⁴⁾

The key question of whether the strategy is proving to be cost-effective has not yet been determined.

Footnotes and Source:

(1) Seow, Helen, Susan King and Vida Vaitonis. "The Impact of Ontario's End-of-Life Care Strategy on End-of-Life Care in the Community," *Healthcare Quarterly* 11, 1 (2008), p. 57.

(2) *Ibid.*, p. 60.

(3) *Ibid.*, p. 61.

(4) *Ibid.*

Inadequate support for family caregivers.

Many are overburdened, particularly those who are caring for loved ones suffering from dementia and individuals with long-term illnesses (often with no hope of cure), those who have multiple responsibilities and those providing care to more than one person.

The public/private debate on funding of home care services. Which services should be funded and delivered through the public system and which ones should clients pay for privately? Should there be a means test, and if so, should it be based on assets or income? As health care researchers Parent and Anderson noted, “There is a growing private market, and so we have to ask why that is and if that is what we want. We have not had that debate.”¹⁵⁸

Inconsistent provision and delivery of home care services to Aboriginal and First Nations peoples. Challenges lie in providing adequate home care to these populations and eliminating or minimizing the differences between the provincial home care program and the on-reserve Health Canada funded *Home Care Program*. The differences make it difficult to offer consistent care delivery. These discrepancies need to be addressed.

Home care for children and youth.

Difficulties include lengthy waiting lists, both for initial diagnosis and services; differences in services offered across the country; and difficulties associated with transitions from pediatric to school services and from child to adult services.

Lack of integration of the home care sector in the continuum of care (acute care, primary care and facility-based long-term care). This is an ongoing challenge, although in some cases we have succeeded admirably (PRISMA, CHOICE, SIPA).

Lack of strategic focus and funding for ICT in the home care sector. Governments are recognizing the vital importance of home care services in meeting the needs of the aging population and of those with chronic diseases. They must also recognize ICT’s effectiveness in this sector and make the necessary investments in ICT.¹⁵⁹

To maximize the effectiveness of home care in improving and maintaining the health of Canadians, home-care programs must have clear goals, be founded firmly on clinical, system and social evidence of effectiveness, form a coherent part of an integrated healthcare system and be grounded in Canadian constitutional and political reality. Adhering to these principles will guide home care safely through the waters of healthcare reform.

— Laurence G. Thompson¹⁶⁰

Recommendations

The Canadian Healthcare Association (CHA) has long advocated for a home and community care program that provides both acute care replacement services and ongoing continuing/chronic care in the community. CHA continues to affirm that all Canadians who require continuing care should receive the right care at the right time in the right setting.

Research projects undertaken in the last decade demonstrate that properly targeted long-term home care services allow individuals to live at home with independence and dignity, and can be valuable and cost-effective in that they either postpone people's need for, or keep people out of, facilities and hospitals. The findings of these research projects indicate that it is time for long-term preventive and maintenance home care services to be placed on the health policy agenda.

The following recommendations outline actionable items that can contribute to the realization of equity, transparency and accountability in home care.

1. Ensure integration and expansion of home care within the continuum of care.

Hollander notes that expanding home care services might not cost as much as some policy-makers fear, as home care systems exist and would simply need additional investment rather than building a new system from scratch.

Some policy-makers may have the misapprehension that focusing on chronic or long-term care may significantly increase costs. In this regard it should be noted that all Provinces and Territories already have well-developed, government-



funded systems of long-term home care. All jurisdictions already provide professional services free of charge. Some provinces such as Manitoba, Ontario and Québec provide home support services without charge under certain conditions. Most other provinces provide them on an income-tested basis. Thus, the cost to “top up” existing systems could be fairly modest if one builds on the systems which already exist. In addition, restructuring resources into a continuing care model will not necessarily require new resources....Change costs would however be incurred.¹⁶¹

1.1 Expand, improve and identify standards for home care to ensure equitable access and to include long-term maintenance and prevention services.

The ability of governments to choose the number and types of services and the delivery models means that home care is more vulnerable to cyclical funding and political change.

When expanding home care, governments should:

- *Make the client’s health and well-being the main priority.*
- *Give equal attention to longer-term maintenance/preventive home care and to short-term post-acute home care.*
- *Examine the Veterans Independence Program (VIP) as a potential model. Studies of the VIP demonstrated the worth (both financial and non-financial) of continuing long-term home care. In addition, the Liberal Task Force on Seniors recommended that the federal government use the VIP as a model to develop a similar program that promotes independent living among seniors.¹⁶²*
- *Focus on a larger role for home care in caring for the mentally ill. Home care can reduce dependence on hospitals. To boost the role of home care in mental health, three barriers must be addressed: amend the fee-for-services schedules for psychiatrists, which currently pay them more for hospital inpatient visits than office visits; change the perception that the primary goal of home treatment is to save money; and find experienced mental health workers to provide the required specialized care at home.¹⁶³*
- *Encourage a greater role for home care in palliative care.*
- *Ensure that the role of the case manager is optimized.*
- *Emphasize integration of care.*
- *Focus on improving home care for children and youth.*

2. Ensure predictable and sustainable funding in home care.

The 1984 *Canada Health Act* applies only to insured health services that cover hospital care (acute, rehabilitation and chronic) and medical services. Home care remains an uninsured service under the Act, listed only as an extended service to which the five principles of the Act do not apply. It therefore has no protection under the Act.

The Health Council of Canada has stated that two weeks of publicly funded home care services to eligible patients is too modest an investment. It therefore urges jurisdictions to expand their home care coverage.¹⁶⁴ This can be accomplished through a variety of methods, proposed by Wanless:

- universal entitlement to social care that is government-supported and not means-tested;
- a social insurance model in which the government acts as the insurer and provides a package of care;
- shared costs between state and individual;
- the capping of individuals' liability after they have paid a certain amount or received services for a certain length of time; and
- a pension-linked savings plan.

In a series of pre-Budget briefs, CHA recommends as a start a \$1 billion investment over three years to support a home care program with ongoing/chronic care services linked to pan-Canadian objectives while respecting provincial/territorial jurisdiction regarding the delivery of care.¹⁶⁵

2.1 Address the issue of co-payments and user fees.

CHA has advocated that *Canada Health Act* medically necessary services must continue to be publicly funded (single-tier) along with acute care replacement home care services. The home care picture is cloudy with regard to home support services. The question is whether governments should pay for these services or not.

At present, some provinces and territories charge for certain services. Shapiro notes that the substantial differences regarding co-payments have historical rather than rational roots.¹⁶⁶

Views on co-payments are mixed. Critics consider them discriminatory, pointing to the fact that they create perverse incentives to use a more costly alternative, and opine that they are not worth the trouble of either collecting or ensuring their fairness. Those in favour of co-payments believe that their goal is not to discourage the use of home care services but rather to recover some costs and thereby improve access to these services. They are of the opinion that co-payments — based on a means-based sliding scale so as not to exclude anyone who cannot afford them — would improve the home care system.

CHA believes that co-payments are acceptable for some services (e.g. home support services for some clients, reasonable accommodation payments for facility-based long-term care) and for pharmaceuticals, provided that this does not reduce access. It believes that fair co-payment levels can be established.

2.2 Expand pharmacare to those receiving home care.

The 2004 Accord stipulates that post-acute (mental and physical) and palliative home care clients receive pharmaceutical coverage. The introduction of national home care standards could extend pharmaceutical coverage for patients receiving home care for a medical condition, whether chronic or acute.

A recent comparison of provincial prescription drug plans and the impact on patients' annual drug expenditures published in the *Canadian Medical Association Journal* finds that considerable discrepancies exist across the country in publicly funded provincial drug plans,

leading to great variations in costs to patients. It concludes: “Although current provincial drug plans provide good protection for isolated groups, most Canadians still have unequal coverage for outpatient prescription drugs.”¹⁶⁷ This statement applies to many people receiving home care services or treatment, as they also typically use prescription drugs.”

2.3 Reduce inequities among and within provinces and territories.

Variations in services exist in numerous aspects of home care, including the application of co-payments and income testing; user fees, range and volume of services; publicly funded services; residency requirements; and client payment of supplies, equipment and drugs used in home care.

2.4 Consider having the funding follow the client to allow for portability.

CHA recommends portability of continuing care services across Canada to cover clients until they meet their residency requirements, thus reducing or eliminating waiting periods for either residential services or community-based services. Portability would prevent clients from losing benefits and services as they move from one part of the country to another to be closer to family caregivers. This recommendation would give continuing care services the same measure of portability, as other types of health care services listed in the *Canada Health Act*.

3. Introduce appropriate and relevant pan-Canadian principles to address a greater integration of home/community care.

3.1 Define and expand the basket of services.

CHA urges the federal government to broaden the basket of publicly funded services available across Canada by implementing a national home, community and long-term care program that is established outside of the *Canada Health Act*, perhaps modelling it after the *Social Union Framework Agreement*, with federal funding available subject to the provinces and territories meeting mutually agreed-upon objectives.¹⁶⁸

CHA has maintained that inability to pay should not prevent patients and clients from receiving needed health services, which includes those provided in the home and community. It seeks to ensure access to health services on the basis of need, not ability to pay.

3.2 Introduce a separate piece of legislation with appropriate and relevant principles to address a greater integration of home, community and long-term care on a pan-Canadian basis.

Developing this arrangement would not necessitate opening up the *Canada Health Act*. The Act requires that access be restricted to persons who require “medically necessary services.” This restriction would medicalize a program that is not simply or exclusively a health program but a health and social service program. There is, in fact, often a greater need for support services than for medical services among post-acute and long-term home care clients. Sometimes their sole need is for support services.

A specific federal/provincial fiscal arrangement on home care (beyond the extended services allocation) is needed. The terms of this arrangement should allow for integration, by the provinces, of home care into continuing care. Financial modalities should promote integration of long-term and acute care. The provinces should be able to adapt home care to the multiple needs of their populations, to the diversity of ethnic and regional characteristics, and to the organizational features of their health and social care system.¹⁶⁹

3.3 Establish minimum standards and accountability mechanisms.

CHA recommends that the federal, provincial and territorial governments and health organizations establish clear expectations, develop explicit quality standards, and demand transparent accountability mechanisms to ensure quality.¹⁷⁰

The Health Council of Canada recommends that governments identify targets, measure and monitor change, and report to Canadians on progress.

Shapiro notes that “in order to ensure the delivery of good quality care in the home, it is important for senior policy-makers to address the issue of home care standards as well as the issue of who is responsible for monitoring them.”¹⁷¹ The Liberal Task Force on Seniors agrees. It recommended “that the federal government collaborate with provincial and territorial governments to establish national standards for home care.”¹⁷²

What would these national standards encompass? The Canadian Association for Community Care (which integrated with CHA in 2006) and the Canadian Home Care Association suggest that a basic set of core services in home and community care in each province and territory should include the following elements:

1. Case management — the assessment of needs, coordination of services and management of resources.
2. Professional care — the services of nurses, social workers, physiotherapists and other professionals, plus access to geriatric assessment and consulting pharmacists and physicians.
3. Assistance with the activities of daily living (washing, dressing) — often referred to as “personal care.”
4. Assistance with the instrumental activities of daily living (activities related to independent living, including preparing meals, managing money, shopping for groceries or personal items, performing housework, and using a telephone) — often referred to as “home-making” or “home support.”
5. Caregiver support — respite and advice.
6. Organized volunteer services — meals on wheels, friendly visiting.
7. Palliative care.
8. Necessary medical supplies and equipment.
9. Day programs.
10. Self-managed care option.
11. Access to subsidized prescription drugs.¹⁷³

Some of these might be difficult to establish in rural and remote communities, but the use of technology (remote imaging, telehealth, teleconferencing, and video conferencing) would facilitate the provision of most of these services.

3.4 Establish strong federal leadership.

The Kirby report pointed out that “the federal government must play a major role in meeting the serious challenges now facing our publicly funded health system.”¹⁷⁴ It underscored that, through its financing role, the federal government can support national principles; ensure that all provinces and territories have the financial resources they need to provide health care (through the redistribution of funds); reform and renew health care; ensure harmonization; have a strong voice in health system restructuring discussions; and provide stable funding.¹⁷⁵

The federal government must take a leading role in developing a pan-Canadian agreement on home care.

The absence of a federal/provincial agreement on a national home care program means that where Canadians live, rather than what they need, determines whether they will have access to services or whether they will have to meet residency requirements, whether they will pay user charges for support services and on what basis they will pay for them, and whether they will be able to count on the continuity of service providers. This situation runs counter to the principles of universality, accessibility, comprehensiveness, portability, and public administration that underpin the policies, administration, management and delivery of other health care services. It is, therefore high time for both levels of government to implement a national home care program that treats all Canadians equally and equitably.¹⁷⁶

4. Provide appropriate supports to both formal and informal (usually family) caregivers.

Caregivers are performing a valuable service — and they deserve more support.

4.1 Minimize the financial burden placed on informal caregivers through means such as amending the *Canada Pension Plan/Quebec Pension Plan*.

The federal government took a major step forward when it introduced the Caregiver Benefit. It could be further strengthened by placing it under the *Canada Pension Plan/Quebec Pension Plan* (CPP/QPP) rather than the *Employment Insurance* program, so that all who give of their time could benefit, not just those with paid non-contractual employment.

A provision in the CPP/QPP to allow for caregiving responsibilities would permit those who leave the labour force to continue to contribute to CPP/QPP. CPP allows parents to drop years of low or no earnings from the calculation of their pension benefits, but no provision exists for other types of caregivers.¹⁷⁷

4.2 Provide additional supports for caregivers.

Other forms of support could be undertaken at a national level:

- recognition of the caregiver role and its importance to society;
- establishment of minimum standards for respite care;
- easier access to information and training; and
- greater social supports for caregivers.

Finally, First Nations and Inuit caregivers require special attention. As many provide care to more than one person, they require better access to home and community care and to respite care.

4.3 Increase the flexibility and availability of respite care.

5. Address the public/private split in terms of access to and quality of services, as well as transparency and accountability.

In Canada, both the public and private sectors have been, and will no doubt continue to be, involved in the delivery of home care services. In addition, services are funded both through public and private funding (out of pocket or insurance).

CHA believes in a publicly funded health system. However, it regards private sector involvement in the delivery of health services as neither a detriment nor a solution to the challenges facing our health system. CHA's position concerning the appropriate public-private mix in the funding and delivery of health care is linked to the principle of access to health services based on health need, not ability to pay. This is a core Canadian value and it cannot be jeopardized. CHA is on record as supporting an evidence-based approach as to when, where and how private funding and/or delivery can occur.¹⁷⁸

Shapiro and others have noted that “the public/private split is hampering the efficiency, cost-effectiveness, and the quality of care delivered to clients.” She cites “the split between the public case management function that determines eligibility, level, locus of service delivery, and cost, and the service delivery function that is often performed by private provider organizations” as one of the major challenges we face.¹⁷⁹

The private sector has a long history in delivering home health care services. Therefore, the issue is to determine how best to overcome the challenges inherent in the public/private split. This can be accomplished in part by fostering better communication through information technology, or by co-locating case managers and those who are paid to provide care, whether through public or private organizations.

The competitive bidding process for home care delivery contracts creates problems for both the profit and not-for-profit service providers as well as for the clients who often lose continuity of service. Two providers, the Red Cross and the Ontario Community Support

Association, offered suggestions to reduce the negative impacts associated with a competitive bidding process:

- Clarify quality indicators based on client outcomes.
- Improve monitoring to ensure that performance expectations are met, and if they are not, establish a time frame for improvement. If improvements are not made in a timely manner, the provider's contract would be terminated.

This would limit competitive bidding to those circumstances where a provider lost a contract due to poor performance, or when a provider voluntarily withdraws from a contract, and would also allow for competition if service volumes increase markedly.¹⁸⁰

6. Invest in health human resources.

6.1 Promote, encourage and strengthen home care health human resources through:

- targeted recruitment and retention, and
- education and training opportunities.

Recruitment and Retention

Home care workers should receive wage parity with similar workers in other areas of the health system. Decreasing the casual workforce and promoting the permanent workforce would boost morale and reduce turnover. Recent Ontario research has found that nurses who work on a casual basis are twice as likely to leave their jobs as those working part time or full time, and that nurses who work in long-term care and home care were the most likely to leave.¹⁸¹ Research also finds that retention of respiratory therapists who work in home and community care is below average, *even when that care is given in a hospital setting*. More investigation is needed to identify the reasons.¹⁸²

Developing career paths and improving benefits would assist in the retention of home care providers. Studies have indicated that more health professionals could be persuaded to work in home care if the full scope of practice were emphasized to a greater degree.¹⁸³ In particular, a marketing strategy to attract more trained home mental health care workers is required.

Education and Training

Greater education and training would permit personal support workers to better deal with the increasing complexity of home care. Ministries of education should consider the recommendations of the Health Professions Regulatory Advisory Council (HPRAC):

- Personal support worker educational programs in community colleges, career colleges, not-for-profit organizations and boards of education should have mandatory standardized educational outcomes.

- Employers should be involved in establishing curriculum and educational outcomes to meet workplace needs.¹⁸⁴

Given that health human resources shortages are expected to remain a challenge for at least the next three decades, strong leadership is needed at the federal, provincial and territorial levels to address this critical issue. CHA has long urged governments to act upon the initiatives in the *Pan-Canadian Health Human Resources Framework and Strategy* that would deal effectively with labour relations issues, including remuneration levels, benefit packages, service contracts, and payment mechanisms for all health care providers.¹⁸⁵ The time has never been more favourable than now.

7. Make greater use of information and communications technology.

Information technology could certainly play a greater role in home care and in the health system overall. Two areas for expansion of the role of ICT are monitoring and managing the conditions of patients with chronic disease and in post-acute care. Home monitoring devices have been used with great success in various *Health Transition Fund* and *Primary Health Care Transition Fund* initiatives as well as in many other pilot projects across the country. Despite this success, home monitoring devices are not yet the norm. (See boxes “Telemonitoring — Efficient, Effective and Eminently Embraceable” and “Looking at Human Help... and Beyond.”)

Two recent studies emanating from the United States revealed that seniors are willing to use technology, such as sensors to detect falls, machines to monitor blood pressure and respiration, and medication dispensers, to help them age safely in their homes.¹⁸⁶

Given that technology can facilitate home care, enable clients to feel safer, give greater peace to them and to their families and friends, and also boost the efficiency of the health system overall, it is important that ICT and other forms of technology be broadly implemented in our health care system. As every comparison with other OECD countries shows, Canada

Telemonitoring — Effective, Efficient and Eminently Embraceable

Home health monitoring, more commonly referred to as “remote patient monitoring,” is a branch of telemedicine that focuses on monitoring the health-related indicators of a patient living at home. The indicators are generally patients’ vital signs, such as oxygen levels, blood pressure and weight.⁽¹⁾ Telemonitoring is proving to be an effective way of monitoring patients with chronic disease, and in fact, technology industry leaders are being advised that this is a growth area.⁽²⁾ Pilot projects in cities such as Calgary, Ottawa, Scarborough, Hamilton and Montreal, and in provinces such as Manitoba and New Brunswick are yielding impressive results and are indicating that telemonitoring:

- reduces hospital admissions and readmissions (in New Brunswick by as much as 85 percent);
- lowers the number of emergency department visits;
- helps patients to better manage their chronic conditions;
- reduces health system costs;
- gives greater assurance that patients follow after-care instructions;
- supports physicians, especially in under-serviced areas;
- saves patients from unnecessary travelling; and
- permits more patients to be monitored, generally by nurses, in less time.

Footnotes and Source:

(1) British Columbia Institute of Technology, “Home Monitoring Technologies in the Community/Home Care Environment,” March 2006. Retrieved April 5, 2008, at: <http://www.winbc.org/files/PDF/Resources/HomeMonitorIndustryPullStudy06.pdf>. p. 3.

(2) *Ibid.*, p. 9.

Looking at Human Help...and Beyond

Norway is thinking well outside the box in its search for home care solutions. It is facing an acute shortage of health care workers and a growing number of elderly persons, and is therefore considering enlisting non-human help in the form of robots and other technological devices. If robots could do housework, and if medical equipment could help clients monitor and care for their health, then the need for health care workers could be lessened. The human workers could then concentrate on giving care.

Source:

ZDNet News, "Short of Staff, Norway Eyes Robot Care for Elderly," Feb. 7, 2008. http://news.zdnet.com/2100-9595_22-6229581.html?tag=nl.e539.

falls short on the use of technology. As a developed country with advanced technological capacities, Canada must address the use of ICT in home care.

In the September 2000 *Communiqué on Health*, First Ministers agreed to work together to strengthen a Canada-wide health infrastructure to improve quality, access and timeliness of health services for Canadians. First Ministers also committed to developing electronic health records and enhancing technologies such as telehealth.¹⁸⁷ Without a strong federal commitment to the

Health Infoway and an extension of its mandate, we will continue to fall behind other countries in health ICT, and the efficiencies that we need to achieve will be difficult to attain.

To enhance the efficiency and effectiveness of Canada's health system, CHA recommends additional investments of \$6.2 billion over five years in order to accelerate the development and implementation of a pan-Canadian electronic health record and to broaden its scope.¹⁸⁸

In 2002, CHA stated: "Without a compatible, pan-Canadian health information system, many improvements to our health system will not be possible. Accountability mechanisms will be halted or drastically reduced in scope. Effective coordination of treatment across the continuum of care will not be possible. Health information technologies are an essential investment that will fundamentally change and improve the delivery and integration of health services."¹⁸⁹ This statement remains true today.

8. Share leading practices and experiences from both within and outside Canada.

Many countries are pioneering novel home care practices, and Canada itself has pockets of excellence. We can build upon the lessons learned at home and abroad (especially from those countries that are facing similar demographic, financial and geographic challenges). Much has been done — and is being done — in home care. It is time to start applying proven strategies within the system.

Pour que les soins à domicile améliorent et maintiennent la santé des Canadiens, les programmes de soins à domicile doivent poursuivre des objectifs clairement définis, être fondés sur des preuves cliniques, systémiques et sociales de leur efficacité, former un volet cohérent d'un système de soins de santé intégré et reposer sur la réalité politique et constitutionnelle du Canada. L'adhésion à ces principes favorisera l'intégration sécuritaire des soins à domicile à la réforme des soins de santé i [trad.]

— Laurence G. Thompson^{1,60}

Recommandations

L'Association canadienne des soins de santé (ACS) plaide depuis longtemps en faveur d'un programme de soins à domicile et communautaires qui offre à la fois des services en remplacement des soins de courte durée ainsi que des soins continus et/ou des soins aux malades chroniques sur une base permanente. L'ACS maintient que tous les Canadiens qui ont besoin de soins continus doivent recevoir les soins appropriés, au bon moment, dans le milieu approprié.

Les études réalisées au cours de la dernière décennie ont démontré que les services de soins à domicile à long terme, s'ils sont bien ciblés, permettent aux personnes de vivre à la maison de manière autonome et avec dignité et peuvent s'avérer précieux et rentables du fait qu'ils retardent ou évitent la vie en établissements et en milieu hospitalier. Les conclusions de ces études indiquent qu'il est temps d'inscrire les soins à domicile à long terme au programme des politiques en santé, car ils assurent une fonction de prévention et de maintien de la santé.

Les recommandations qui suivent décrivent des mesures pragmatiques susceptibles d'amener équité, transparence et responsabilisation dans les soins à domicile.

1. Assurer l'intégration et l'expansion des soins à domicile dans le continuum de soins.

Hollander souligne que l'expansion des services de soins à domicile ne coûterait pas si cher que certains décideurs ne le craignent, car les systèmes de soins à domicile existent déjà. Nul besoin de partir de rien, mais simplement d'investir des fonds additionnels.



Certains décideurs craignent une augmentation considérable des coûts s'ils mettent l'accent sur les soins aux maladies chroniques ou les soins de longue durée. À cet égard, il importe de souligner que toutes les provinces et les territoires ont déjà des systèmes de soins à domicile à long terme bien établis et subventionnés par des fonds gouvernementaux. Toutes les autorités fournissent déjà gratuitement des services professionnels. Certaines provinces, comme le Manitoba, l'Ontario et le Québec, offrent gratuitement des services de soutien à domicile sous certaines conditions. La plupart des autres provinces offrent ces soins en fonction des revenus. En conséquence, les coûts requis pour bonifier les systèmes existants seraient relativement modestes si l'on se fondait sur les systèmes qui existent déjà. De plus, la réorganisation des ressources en un modèle de soins continus n'exigera pas nécessairement l'ajout de nouvelles ressources ... Il faut toutefois s'attendre à encourir des frais pour opérer les changements.¹⁶¹

1.1 Étendre et améliorer les soins à domicile et établir des normes pour assurer l'accès équitable et inclure des services de maintien de longue durée et de prévention.

Les soins à domicile sont plus sensibles face aux financements cycliques et aux changements politiques du fait que les gouvernements ont la capacité de choisir le nombre et les types de services et les modèles de prestation.

Les gouvernements qui développeront les soins à domicile devraient :

- *Faire de la santé et du bien-être des clients la principale priorité.*
- *Accorder une attention égale aux soins de maintien à domicile et de prévention à plus long terme et aux soins à domicile postactifs à court terme.*
- *Examiner le Programme pour l'autonomie des anciens combattants (PAAC) comme modèle potentiel. Les études du PAAC ont démontré la valeur (financière et non financière) des soins à domiciles continus de longue durée. De plus, le groupe de travail libéral sur les aînés a recommandé au gouvernement fédéral de s'inspirer du PAAC pour concevoir un programme similaire permettant aux personnes âgées de vivre de façon autonome.¹⁶²*
- *Accorder un plus grand rôle aux soins de la maladie mentale dans les soins à domicile. Les soins à domicile peuvent réduire la dépendance à l'égard des hôpitaux. Pour que les soins à domicile jouent un plus grand rôle en santé mentale, il faut surmonter les trois obstacles suivants : modifier les barèmes de rémunération à l'acte des psychiatres qui sont plus élevés à l'heure actuelle pour les consultations de patients hospitalisés que pour les consultations en cabinet; changer la perception que l'on a que le principal objectif du traitement à domicile est de faire économiser de l'argent; et trouver des travailleurs de la santé mentale expérimentés prêts à dispenser à domicile les soins spécialisés nécessaires.¹⁶³*
- *Encourager un plus grand rôle des soins à domicile en soins palliatifs.*
- *Optimiser le rôle du gestionnaire de cas.*
- *Insister sur l'intégration des soins.*
- *Améliorer les soins à domicile pour les enfants et les jeunes.*

2. Assurer le financement prévisible et durable des soins à domicile.

La *Loi canadienne sur la santé* de 1984 (la Loi) ne s'applique qu'aux services de santé assurés qui couvrent les soins hospitaliers (soins de courte durée, réadaptation, soins chroniques) et les services médicaux. Les soins à domicile ne sont pas assurés en vertu de la Loi. Ils font partie des services étendus auxquels les cinq principes de la Loi ne s'appliquent pas. Ils ne sont donc pas protégés par la Loi.

Le Conseil canadien de la santé a déclaré que la prise en charge de deux semaines de services de soins à domicile financés par le gouvernement pour les patients admissibles représente un investissement trop modeste. Il incite les administrations à élargir leur couverture des soins à domicile.¹⁶⁴ Wanless propose plusieurs méthodes pour y arriver :

- droit universel à des soins sociaux soutenus par les gouvernements et non liés aux revenus;
- modèle d'assurance sociale selon lequel le gouvernement agit comme l'assureur et offre un ensemble de soins;
- partage des coûts entre l'État et le citoyen;
- établissement de seuils à la responsabilité d'une personne qui a payé un certain montant ou reçu des services pendant une certaine période;
- plan d'épargne relié au régime de retraite.

Dans une série de mémoires prébudgétaires, l'ACS recommande d'abord un investissement de 1 milliard \$ sur trois ans pour soutenir un programme de soins à domicile, incluant des services de soins prolongés/aux malades chroniques, lié aux objectifs pancanadiens et respectant la juridiction provinciale/territoriale relative à la prestation des soins.¹⁶⁵

2.1 Examiner la question de la participation aux coûts et des tickets modérateurs.

L'ACS a toujours préconisé que les services médicalement nécessaires en vertu de la *Loi canadienne sur la santé* continuent d'être financés par les fonds publics (un seul palier), de même que les services de soins à domicile en remplacement des soins de courte durée. La situation des soins à domicile est plus trouble en ce qui a trait aux services de soutien à domicile. La question est de savoir si les gouvernements devraient ou non payer pour ces services.

Actuellement, des frais sont imposés pour certains services dans quelques provinces et territoires. Shapiro souligne que les principales différences entre les provinces sur le plan de la participation aux coûts ont des racines historiques plutôt que rationnelles.¹⁶⁶

Les opinions sur la participation aux coûts sont partagées. Ceux qui s'y opposent la jugent discriminatoire et soulignent qu'elle crée des incitatifs pervers à utiliser une autre solution plus coûteuse. Ils croient que le trouble de percevoir cette quote-part et de s'assurer qu'elle est équitable n'en vaut pas la peine. Ceux qui sont en faveur croient au contraire qu'elle ne vise pas à empêcher les gens d'utiliser les services de soins à domicile, mais plutôt à récupérer certains frais permettant d'en améliorer l'accès. Ils sont d'avis que la participation aux coûts, établie selon un tarif dégressif basé sur les revenus de manière à ne pas exclure les personnes incapables de payer, améliorerait le système de soins à domicile.

L'ACS croit que la participation aux coûts est acceptable pour certains services, comme les services de soutien à domicile pour certains clients, la participation raisonnable aux coûts de l'hébergement en établissement de soins de longue durée et le ticket modérateur sur les produits pharmaceutiques, à la condition que cela ne réduise pas l'accès aux soins. L'ACS croit qu'il est possible de déterminer des niveaux équitables de participation aux coûts.

2.2 Étendre l'assurance-médicaments à ceux qui reçoivent des soins à domicile.

L'Accord de 2004 prévoit que les clients qui reçoivent des soins à domicile, qu'il s'agisse de soins postactifs (pour les maladies mentales et les maladies physiques) ou de soins palliatifs, aient droit au remboursement des médicaments. L'introduction de normes nationales en matière de soins à domicile pourrait étendre la couverture des médicaments aux patients qui reçoivent des soins à domicile pour des troubles médicaux chroniques ou aigus.

Une récente comparaison des régimes d'assurance-médicaments des provinces et de leurs effets sur les dépenses annuelles des patients publiée par le *Journal de l'Association médicale canadienne* conclut qu'il existe des variations considérables dans les régimes publics provinciaux d'assurance-médicaments, ce qui mène à des variations importantes des dépenses annuelles des patients. L'étude conclut : « Bien que les régimes d'assurance-médicaments provinciaux actuels offrent une bonne protection à des groupes isolés, la plupart des Canadiens ont toujours une protection inégale en matière de médicaments sur ordonnance pour patients non hospitalisés. »¹⁶⁷ Ce constat s'applique également aux nombreuses personnes qui reçoivent des services ou des traitements à domicile.

2.3 Réduire les iniquités au sein des provinces et territoires et entre ceux-ci.

Dans le pays, on observe des variations de services dans les domaines suivants : les modalités relatives à la participation aux coûts et à la prestation fondée sur les revenus; les tickets modérateurs, la gamme et le volume des services; les services subventionnés par des fonds publics; les exigences de résidence; et le paiement par les clients de fournitures, équipements et médicaments utilisés dans les soins à domicile.

2.4 Envisager des mécanismes faisant en sorte que le financement suive le client pour favoriser la transférabilité.

L'ACS recommande également la transférabilité des services de soins de longue durée partout au Canada, pour couvrir les clients jusqu'à ce qu'ils répondent aux exigences d'admission en établissement, réduisant ou éliminant ainsi les périodes d'attente pour des services en établissement ou des services communautaires. Ainsi, les clients ne perdraient pas leurs avantages et leurs services en se déplaçant d'une région du pays à une autre pour se rapprocher de leurs aidants naturels. La transférabilité s'appliquerait de la même façon que dans la *Loi canadienne sur la santé*.

3. Adopter des principes pancanadiens appropriés et pertinents pour mieux intégrer les soins à domicile et les soins communautaires.

3.1 Définir et étendre la gamme de services.

L'ACS presse le gouvernement fédéral d'élargir la gamme de services financés par les deniers publics disponibles au Canada en instaurant un programme national de soins à domicile, communautaires et de longue durée créé en dehors de la Loi canadienne sur la santé, possiblement inspiré de l'Entente-cadre pour l'union sociale, en vertu duquel le financement fédéral serait assujéti à l'atteinte d'objectifs convenus de concert avec les provinces et territoires.¹⁶⁸

L'ACS maintient que l'incapacité de payer ne devrait pas empêcher des patients et des clients de recevoir les services de santé dont ils ont besoin, y compris les services offerts à domicile et dans la communauté. L'ACS prône l'accès aux services de santé sur la base des besoins et non pas sur la base de la capacité de payer.

3.2 Adopter une loi distincte qui établit les principes appropriés et pertinents pour mieux intégrer les soins à domicile, communautaires et de longue durée sur une base pancanadienne.

Pour ce faire, il n'est pas nécessaire de modifier la *Loi canadienne sur la santé*. La Loi exige que l'accès soit restreint aux personnes qui ont besoin de « services médicalement nécessaires ». Cette restriction médicaliserait un programme qui n'est pas simplement ou exclusivement un programme de santé, mais un programme de services en santé et de services sociaux. On compte plus de clients en soins postactifs et en soins de longue durée qui ont besoin de services de soutien que de clients qui ont besoin de services médicaux. Parfois ils ont uniquement besoin de services de soutien.

Il est nécessaire de conclure des accords fiscaux fédéral/provinciaux particuliers pour les soins à domicile (au-delà de l'allocation pour des services complémentaires). Les modalités de tels accords devraient permettre aux provinces d'intégrer les soins à domicile aux soins de longue durée. Les modalités financières devraient promouvoir l'intégration des soins de courte et de longue durée. Les provinces devraient pouvoir adapter les soins à domicile aux multiples besoins de leur population, à la diversité ethnique et régionale et aux caractéristiques organisationnelles de leur système de santé et de services sociaux.¹⁶⁹

3.3 Établir des normes minimales et des mécanismes de reddition de compte.

L'ACS recommande que les gouvernements fédéral, provinciaux et territoriaux et les organisations de la santé déterminent des attentes claires, élaborent des normes de qualité explicites et demandent la mise en place de mécanismes de reddition de compte transparents pour assurer la qualité.¹⁷⁰

Le Conseil canadien de la santé recommande que les gouvernements déterminent des cibles, mesurent et surveillent le changement et fassent rapport aux Canadiens sur les progrès réalisés.

Selon Shapiro, « il est important, pour garantir la prestation de soins à domicile de bonne qualité, que les principaux décideurs se penchent sur la question des normes des soins à domicile et précisent qui est chargé de leur suivi. »¹⁷¹ Le groupe de travail libéral sur les aînés abonde dans le même sens. Il a recommandé que « le gouvernement fédéral collabore avec les gouvernements provinciaux et territoriaux à l'établissement de normes nationales en matière de soins à domicile. »¹⁷²

Que comprendraient ces normes nationales? L'Association canadienne des soins et services communautaires (qui a fusionné avec l'ACS en 2006) et l'Association canadienne des soins et services à domicile suggèrent que les provinces et territoires offrent les services et soins communautaires et à domicile de base suivants :

1. Gestion des cas – l'évaluation des besoins, la coordination des services et la gestion des ressources.
2. Soins professionnels – les services d'infirmières, de travailleurs sociaux, de physiothérapeutes et d'autres professionnels, ainsi que l'accès à des évaluations en gériatrie et des consultations avec des pharmaciens et des médecins.
3. Aide à l'accomplissement des activités quotidiennes (se laver, s'habiller) – que l'on appelle souvent « soins personnels ».
4. Aide à l'accomplissement des activités instrumentales de la vie quotidienne (activités ayant trait à la vie autonome, comme préparer les repas, gérer ses finances, faire des courses, s'occuper de l'entretien ménager et utiliser un téléphone) – que l'on appelle souvent « soutien » ou « maintien à domicile ».
5. Soutien aux aidants naturels – services de relève et conseils.
6. Services de bénévoles structurés – popotes roulantes, visites amicales.
7. Soins palliatifs.
8. Fournitures médicales et équipements nécessaires.
9. Programmes de jour.
10. Option d'autogestion des soins.
11. Accès subventionné aux médicaments sur ordonnance.¹⁷³

Certains de ces services peuvent être difficiles à instaurer dans des collectivités rurales et éloignées, mais l'utilisation de la technologie, comme l'imagerie à distance, la télésanté, la téléconférence et la vidéoconférence faciliterait la prestation de la plupart de ces services.

3.4 Établir un leadership fédéral solide.

Le rapport Kirby a souligné que « le gouvernement fédéral doit jouer un rôle important dans la résolution des graves problèmes auquel est présentement confronté le système de santé public. »¹⁷⁴ Il a également souligné que par son rôle en matière de financement, le gouvernement fédéral peut : soutenir des principes nationaux, veiller à ce que toutes les provinces et les territoires disposent des ressources financières nécessaires pour répondre aux besoins de leur population en matière de soins de santé (au moyen de la redistribution des fonds); réformer et renouveler les soins de santé; assurer l'harmonisation; avoir voix au chapitre lorsqu'il s'agit de restructurer le système de santé; et offrir du financement stable et prévisible.¹⁷⁵

Le gouvernement fédéral doit jouer un rôle de chef de file dans l'élaboration d'une entente pancanadienne sur les soins à domicile.

L'absence d'entente fédérale-provinciale sur un programme de soins à domicile national signifie que le lieu de résidence des Canadiens, plutôt que leurs besoins, est déterminant en ce qui concerne leur accès à des services, les critères auxquels ils devront satisfaire pour recevoir des soins en résidence, les frais modérateurs qu'ils auront à payer pour des services de soutien et selon quelles modalités, ainsi que la continuité dans les fournisseurs assurant ces services. La situation est contraire aux principes d'universalité, d'accessibilité, d'intégralité, de transférabilité et d'administration publique qui sous-tendent les politiques, l'administration, la gestion et la prestation d'autres services de santé. Il est donc grandement temps que les deux paliers de gouvernement mettent en œuvre un programme de soins à domicile national qui traite tous les Canadiens sur un pied d'égalité et équitablement.¹⁷⁶

4. Offrir les soutiens appropriés aux intervenants professionnels et aux aidants naturels (généralement des membres de la famille).

Les intervenants rendent des services précieux – et ils méritent un plus grand soutien.

4.1 Réduire le fardeau financier imposé aux aidants naturels par diverses mesures, comme des modifications au Régime de pensions du Canada et au Régime des rentes du Québec.

Le gouvernement fédéral a fait un grand pas en avant lorsqu'il a mis en place les prestations pour les aidants naturels. Il pourrait toutefois aller plus loin en intégrant une telle mesure au Régime de pensions du Canada (RPC) et au Régime des rentes du Québec (RRQ) plutôt qu'au Programme d'assurance-emploi, de sorte que tous ceux qui donnent de leur temps pourraient en profiter et pas seulement les titulaires d'emplois rémunérés.

L'insertion d'une clause au RPC et au RRQ qui reconnaîtrait les services rendus par les aidants naturels permettrait à ceux qui quittent leur emploi pour soigner un proche de continuer à contribuer au RPC ou au RRP. Le RPC permet aux parents d'exclure les années de revenus faibles ou nuls du calcul de leurs rentes de retraite, mais aucune clause de ce type n'existe pour les aidants naturels.¹⁷⁷

4.2 Offrir un soutien additionnel aux aidants naturels.

D'autres mesures de soutien sont nécessaires et pourraient être entreprises à une échelle nationale :

- reconnaissance du rôle des aidants naturels et de son importance dans la société
- création de normes minimales relatives aux soins de relève
- accès plus facile à de la formation et de l'information
- plus grands appuis sociaux aux aidants naturels

Finalement, les aidants naturels des Premières nations et des Inuits requièrent une attention

spéciale. Comme bon nombre d'entre eux offrent des soins à plus d'une personne, ils doivent avoir un meilleur accès aux soins à domicile, aux soins communautaires et aux soins de relève.

4.3 Améliorer la flexibilité et la disponibilité des soins de relève.

5. Examiner la question du partage public/privé en matière d'accès aux services, de qualité des services, de transparence et de reddition de comptes.

Au Canada, le secteur public et le secteur privé participent tous deux à la prestation des services de soins à domicile et continueront sans aucun doute à le faire. En outre, les services sont financés par des fonds publics et par des fonds privés (défraiements ou assurance).

L'ACS croit en un système de santé public. Toutefois, elle ne voit pas la participation du secteur privé à la prestation des services de santé comme un désavantage ni comme une solution aux défis de notre système de santé. La position de l'ACS concernant la combinaison appropriée de financement et/ou de prestation de soins de santé par le secteur privé est liée au principe de l'accès à des services qui reposent sur le besoin de soins et non pas sur la capacité de payer. C'est une valeur canadienne fondamentale qui ne peut être mise en péril. L'ACS a toujours soutenu une approche fondée sur des preuves en ce qui concerne le moment, le lieu et la façon de financer ou d'offrir des soins privés.¹⁷⁸

Shapiro et d'autres ont souligné que : « le clivage entre les secteurs public et privé dans les services de soins à domicile nuit à l'efficacité, à la rentabilité et à la qualité des soins dispensés aux clients. » Elle ajoute que « la coupure entre la fonction de gestion publique des cas, qui détermine le droit à des services, leur niveau, le lieu de leur prestation et leur coût, d'une part, et la fonction de prestation des services, d'autre part, qui revient souvent à des organisations de fournisseurs privés » est l'un des plus grands défis auxquels nous sommes confrontés.¹⁷⁹

Le secteur privé a une longue expérience des services de soins à domicile. La question est donc de déterminer comment relever les défis inhérents au partage entre les secteurs public et privé. Pour ce faire, on peut notamment améliorer les communications, grâce à la technologie de l'information, ou installer dans un même endroit les gestionnaires de cas et les personnes rémunérées pour offrir des soins, que ce soit par le biais d'organisations publiques ou privées.

Le processus d'appels d'offres concurrentiels pour l'attribution des contrats de services de soins à domicile crée des problèmes aux fournisseurs de services à but lucratif et à but non lucratif, de même qu'aux clients qui perdent souvent la continuité des services. Deux fournisseurs, la Croix-Rouge et l'Ontario Community Support Association ont présenté leurs suggestions pour atténuer les impacts négatifs des appels d'offres concurrentiels :

- clarifier les indicateurs de qualité basés sur les résultats pour les clients.
- améliorer la surveillance pour assurer la performance voulue, et, dans le cas contraire, déterminer un délai pour démontrer une amélioration. Si aucune amélioration n'est constatée dans les délais prévus, le contrat du fournisseur serait résilié.

Ainsi, les appels d'offres concurrentiels se limiteraient aux situations où un fournisseur perd son contrat à cause de sa piètre performance ou met fin volontairement à son contrat, ou encore en cas d'augmentation des volumes de services.¹⁸⁰

6. Investir dans les ressources humaines en santé.

6.1 Promouvoir, encourager et renforcer les ressources humaines en santé des soins à domicile par :

- le recrutement et le maintien en poste de personnel ciblé;
- les possibilités d'éducation et de formation.

Recrutement et maintien en poste

Les travailleurs des soins à domicile devraient avoir la parité salariale avec les travailleurs qui effectuent des tâches semblables dans d'autres domaines du système de santé. La diminution des emplois occasionnels et la promotion des emplois permanents sont des mesures qui auraient un effet positif sur le moral de la main-d'œuvre et qui contribueraient à diminuer le roulement de personnel. Une étude récente en Ontario a conclu que les infirmières qui ont un emploi occasionnel quittent leur emploi deux fois plus souvent que celles qui travaillent à temps partiel ou à temps plein et que les infirmières qui travaillent dans des établissements de soins de longue durée et des services de soins à domicile sont celles qui ont le plus tendance à quitter leur emploi.¹⁸¹ L'étude a également constaté que le taux de maintien en fonction des inhalothérapeutes qui travaillent en soins à domicile et en soins communautaires est plus faible, *même quand ces soins sont donnés en milieu hospitalier*. Il faudra approfondir la question pour en identifier les raisons.¹⁸²

Le développement de cheminements de carrière et l'amélioration des avantages aideraient à retenir en poste les intervenants au soins à domicile. Des études ont indiqué que l'on convaincrat un plus grand nombre de professionnels de la santé de travailler dans le domaine des soins à domicile si l'on mettait davantage accent sur la possibilité d'exercer pleinement leurs compétences.¹⁸³ Il importe particulièrement d'établir une stratégie de marketing pour attirer plus de travailleurs en soins de santé mentale à domicile.

Éducation et formation

Les préposés aux services de soutien à la personne seraient mieux en mesure de faire face à la complexité croissante des soins à domicile s'ils étaient mieux formés. Les ministères de l'Éducation devraient examiner attentivement les recommandations formulées par le Conseil consultatif de réglementation des professionnels de la santé (CCRPS) :

- élaborer des résultats d'apprentissages uniformes et obligatoires pour les programmes de formation des préposés aux services de soutien à la personne dans les collèges communautaires, les collèges d'enseignement professionnel, les organismes à but non lucratif et les conseils de l'éducation;

- que soit développée la participation des employeurs dans l'établissement des programmes d'études et des résultats d'apprentissage en fonction des besoins du marché du travail.¹⁸⁴

On prévoit que le problème des pénuries de ressources humaines en santé se fera sentir pendant au moins trente ans encore. Il faut donc que les gouvernements fédéral, provinciaux et territoriaux fassent preuve d'un solide leadership. L'ACS demande depuis longtemps aux gouvernements d'agir selon la Stratégie pancanadienne relative aux ressources humaines en santé et d'instaurer des mesures qui traitent efficacement des questions de relations de travail, y compris les niveaux de rémunération, les avantages sociaux, les contrats de services et les mécanismes de paiement pour tous les fournisseurs de soins de santé.¹⁸⁵ Le moment n'a jamais été aussi propice que maintenant pour aller de l'avant.

7. Utiliser davantage les technologies de l'information et des communications.

Les technologies de l'information et des communications (TIC) pourraient certainement jouer un plus grand rôle dans les soins à domicile et le système de santé en général. Elles laissent place à de l'expansion dans deux domaines en particulier : le suivi et la gestion de l'état des patients souffrant de maladies chroniques et recevant des soins postactifs. Certains dispositifs de surveillance à domicile ont été utilisés avec grand succès dans divers programmes du Fonds pour l'adaptation des services de santé et du Fonds pour l'adaptation des soins de santé primaire, de même que dans divers projets pilotes menés à la grandeur du pays. Malgré ces réussites, l'utilisation de ces dispositifs n'est pas encore devenue la norme. (Voir « Telemonitoring — Efficient, Effective and Eminently Embraceable » et « Looking at Human Help... and Beyond. »)

Deux études américaines récentes ont révélé que les personnes âgées sont désireuses d'utiliser la technologie, comme les détecteurs de chutes, les appareils qui surveillent la pression du sang et la respiration et les distributeurs de médicaments qui les aident à vieillir en sécurité dans leurs domiciles.¹⁸⁷

Puisque cette technologie peut faciliter la prestation des soins à domicile, donner un sentiment de sécurité aux clients et à leurs familles et amis et améliorer l'efficacité du système de santé en général, il est important que les TIC et les autres formes de technologie soient instaurées à une grande échelle dans notre système de soins de santé. Dans ce domaine comme dans bien d'autres, les pays de l'OCDE sont plus avancés que nous. En tant que pays développé doté de capacités technologiques de pointe, le Canada doit se pencher sur la question de l'utilisation des TIC dans les soins à domicile.

Dans leur *Communiqué sur la santé*, de septembre 2000, les premiers ministres canadiens convenaient d'unir leurs efforts pour créer un cadre complet à la grandeur du pays en vue d'améliorer la qualité des services, l'accès aux services et la prestation en temps opportun des services de santé offerts aux Canadiens. Les premiers ministres se sont également engagés à développer les dossiers de santé électroniques et les nouvelles technologies, comme la télésanté.¹⁸⁷ Sans un profond engagement fédéral envers Inforoute Santé du Canada et

l'extension de son mandat, nous continuerons de nous laisser distancer par les autres pays en matière de TIC de la santé et nous pourrions difficilement atteindre les niveaux d'efficacité souhaitables.

Pour améliorer l'efficacité et l'efficacit  du syst me de sant  du Canada, l'ACS recommande des investissements additionnels de 6,2 milliards \$ sur cinq (5) ans en vue d'acc l rer le d veloppement et la mise en oeuvre d'un dossier de sant   lectronique pancanadien et d'en  largir la port e.¹⁸⁸

En 2002, l'ACS  non ait que : « Sans un syst me d'information pancanadien compatible en sant , plusieurs am liorations   notre syst me de sant  ne pourront  tre apport es. Les m canismes de reddition de compte seront mis en veilleuse ou verront leur port e consid rablement r duite. La coordination efficace des traitements   travers le continuum des soins ne sera pas possible. Les technologies de l'information en sant  sont un investissement essentiel qui changera fondamentalement et qui am liorera la prestation et l'int gration des services de sant . »¹⁸⁹ Cet  nonc  est toujours vrai aujourd'hui.

8. Partager les pratiques exemplaires et les exp riences du Canada et d'ailleurs.

Bien des pays exp rimentent de nouvelles pratiques en mati re de soins   domicile et le Canada lui-m me abonde en exemples de r ussite. Nous pouvons tirer parti des exp riences du Canada et de l' tranger (particuli rement des pays qui ont des profils d mographiques, financiers et g ographiques semblables aux n tres). On a fait beaucoup – et on fait encore beaucoup – dans le domaine des soins   domicile. Il est temps de commencer   appliquer les strat gies qui ont fait leur preuve   la grandeur du syst me.

There is no shortage of renewal efforts in primary health care and home care. But it is now time to start applying proven strategies across the system — and it is time for jurisdictions to identify clear targets, measure their efforts, and show Canadians how their health care system is changing for the better.

— Health Council of Canada¹⁹⁰

Conclusion

From the Margins to the Mainstream

The quotation from Hans Stein at the beginning of this brief highlights the fact that health systems are not static, that they evolve and reflect the changing priorities of society as a whole.

Tommy Douglas foresaw that the publicly funded health system he pioneered in this country would change with time. He identified two phases for medicare. The first phase would usher in universal public insurance for physician and hospital care. The second phase would extend medicare to home care, long-term care, community care, pharmacare, and initiatives that would address the social determinants of health and the disparities that are reflected in poor health outcomes. In this phase, emphasis would be placed on managing health care better, through wait list management, teamwork, integration, evidence-based practice and other innovations.¹⁹¹ If Canada is embarking on the second phase, then home care must be a cornerstone of a renewed and more efficient health care system.

Home care cannot meet all of the needs of patients; some require facility-based long-term care or hospitalization. Home care is an excellent choice for some patients but a poor choice for others. It will not solve our health budget problems, although it is likely to alleviate some of them. It is not a panacea for all the issues facing the health system. (See box “New Brunswick’s Extramural Program: Lessons Learned.”)

In 2003, Shapiro noted in her examination and summary of the *Health Transition Fund* initiatives:



New Brunswick's Extra-Mural Program: Lessons Learned

New Brunswick developed its province-wide home health care strategy, the *Extra-Mural Program*, 25 years ago. Since then, the program has become an integration model for primary care, home care and rehabilitation services. Its name and mandate recognize the fact that, increasingly, care takes place beyond the walls of a hospital.

Anyone wishing to improve a home care program would do well to consider these five well-considered lessons.

1. The cornerstone of quality home health care services (whether they are acute care services, palliative care or rehabilitation) is the comprehensive team working collaboratively to meet the needs of the client and family. This team must include the client and family as partners in the provision of care and decision making in the same manner that collaborations with facility- and community-based health providers are deemed absolutely essential to the delivery of health care services in the home.
2. Increased utilization of acute home care services in New Brunswick has been the result of several factors, including:
 - planned design of a comprehensive home health care system;
 - awareness of the gaps in health care services, recognizing the potential for care in the community and development of solutions to address the gaps;
 - commitment to the importance of the role of home and community care and the advantages of caring for individuals at home by all stakeholders;
 - an increase in ambulatory/day surgery procedures that require home health care as a follow up;
 - response to technological advances in health care (i.e. equipment);
 - consumer demand for service in the home (i.e. palliative care); and
 - physician support of the program.
3. Home health care needs to communicate what it can deliver but also, more importantly, what it cannot. One must guard against the assumption that because something can be done at home, it should be done at home, it must be done at home. This alone is not sufficient justification; it ignores many of the complex factors associated with the home environment, including suitability of the home for the service

...[there is] an increasing trend to make home care the vehicle for delivering services that are costly and that, in some cases, should be provided by other sectors....Home care is being pressured to speed up in-hospital or hospital emergency room discharges even when persons need complex, intensive, and, therefore, costly care at home. As well, home care is being pressed to speed up transfers from hospital to long-term care facilities of persons who require alternative resources for a period of convalescence that might result in their being able to return home. Finally, there is a disquieting increase in the number of initiatives that make home care the vehicle for delivering services that have traditionally and appropriately been within the mandate of public health.¹⁹²

Home care should not eclipse long-term care or seniors' housing. Both require more attention and more resources. The *Saskatchewan Health Transition Fund* initiative *An Exploratory Study of the Impact of Home Care on Elderly Clients over Time* found that seniors' housing is more effective than preventive home care in keeping seniors alive and out of facility-based long-term care and that it results in lower overall health service costs. This was but one study, and its results should be interpreted with caution, but its message reminds us that home care is indeed only one part — albeit a vital part — of our health and social system.

Governments must come to regard home care as something more — and something less — than a cost-saving measure. Home care has its place in the continuum of care. It can substitute for acute care, post-acute care, facility-based long-term care or convalescent care. But this is not always the case. It is in the best economic interests of the health system overall if those who require, and whose health status would benefit from, home care receive it.

It has become apparent that when we focus on reforming one area of the health system and give less attention to other areas, our efforts are doomed to failure. In our preoccupation with acute care and wait times, we have not committed the necessary resources to home and community care, to the detriment of the system as a whole.

Yet despite the evidence from all quarters and over many years that an expanded role for home care is necessary, policy-makers show continued ambivalence on the subject of greater public funding for home care, particularly for longer-term maintenance and preventive care, and for reducing inequities across the country. This view continues, despite the fact that "...even modest investments in long-term home care, and a revalidation of long-term home care as an integral part of home care in Canada, are good strategic policy investments."¹⁹³

Other countries have been much more proactive. Australia is two decades ahead of Canada in establishing a national home care program and is more realistic in its support of caregivers. The United Kingdom is focusing on home care as it continues to renew its health system. Home care has a high profile in the public health systems of other developed countries, including Denmark, Sweden, Japan, Germany and France. It is time for Canadian policy-makers to make home care (both short- and long-term) a priority.

Although various jurisdictions in this country have moved the home care agenda forward, policies generally do not reflect the shifts that have occurred in how and where we deliver care. Home care is moving from the margins to the mainstream, and its role is unlikely to diminish in importance over the next few decades.

(i.e. safety for the client and service providers), the presence or absence of a support network, and the capacity of the support network and service providers to provide required care.

4. Home health care is not "cheap" care, it is not second class care; it is first class care appropriate to the needs of the client/family. Unfortunately, home health care is often promoted as the panacea to health care problems, the bottom line benefits exaggerated. Instead, the home should be promoted as one of many appropriate locations for service delivery.
5. It is challenging to fund the growth of home health care within an environment of growing pressures on the entire health care system. The same pressures affecting institutional care are also impacting home health care services (e.g. rising costs of drugs, paucity of health human resource shortages, technological advances in equipment and interventions).

Source:

Government of New Brunswick, *Healthcare Without Walls: The New Brunswick Extra-Mural Program*. <http://www.gnb.ca/0051/0384/pdf/1985e.pdf>.

It is time for policy-makers to acknowledge this fact and address the current challenges facing the home care sector — all of which can be overcome with sufficient political will and appropriate resource allocation. The home care journey is not complete and our destination will not be reached unless and until policy-makers commit their efforts to achieving a fully integrated health system (with accountability and standards) in which home care plays an important role.

Notes

- 1 Ivan Lewis, Parliamentary Under Secretary of State for Care Services (England). "Now the elderly will get equal rights." *The Observer*, June 24, 2007. Retrieved April 7, 2008, at: <http://www.guardian.co.uk/commentisfree/2007/jun/24/comment.longtermcare>.
- 2 Senator Michael Kirby in Duncan Sinclair, "Speaking with Michael Kirby," *Healthcare Quarterly* 5,4 (2002), pp. 32–39.
- 3 According to the National Health Expenditure Database 1975–2008, in 2008, hospitals were expected to account for 28% of total health spending, with physicians expected to account for an estimated 13.4% of total spending. Canadian Institute for Health Information, *National Health Expenditure Trends, 1975–2008*, 2008, p. xii.
- 4 Aleck Ostry, *Change and Continuity in Canada's Health Care System*, p. 233.
- 5 Richard W. Taylor, "The Future of Home Healthcare in Canada," *CARP Action*, Feb. 2006, p. 2.
- 6 Malcolm Anderson and Karen Parent, "Care in the Home: Public Responsibility — Private Roles." Paper prepared for the Dialogue on Health Reform, June 2000, p. 22.
- 7 Federal-Provincial-Territorial Advisory Committee on Health Services (ACHS) Working Group on Continuing Care, *Technical Report 4: Case Study on Resource Allocation in Home Care—Saskatchewan and Nova Scotia*, May 2000, pp. 1–2. Part of the series *The Identification and Analysis of Incentives and Disincentives and Cost-Effectiveness of Various Funding Approaches for Continuing Care*.
- 8 From FPT Working Group on Home Care, A Working Group of the FPT Subcommittee on Long-Term Care, *Report on Home Care*, Health Canada, 1990.
- 9 Canadian Home Care Association website, CHCA Initiatives page, at: <http://www.cdnhomecare.ca/content.php?sec=5>.
- 10 Ibid.
- 11 Evelyn Shapiro, *Home Care*, p. ii. Part of *Sharing the Learning: The Health Transition Fund Synthesis Series*. Health Canada, 2002.
- 12 From Marcus J. Hollander and E.R. Walker, *Report of Continuing Care Organization and Terminology*. Ottawa: Division of Aging and Seniors, Health Canada, 1998. In the Canadian Nurses Association, *A National Approach to Home and Community Care: Through the Lens of the Canada Health Act*, March 2000, pp. 22–24.
- 13 Patricia M. Baranek, Raisa B. Deber and A. Paul Williams, *Almost Home: Reforming Home and Community Care in Ontario*, pp. 4, 303.
- 14 Canadian Home Care Association, *Portraits of Home Care: A Picture of Progress and Innovation*, 2003, p. 3.
- 15 Canadian Home Care Association, *Portraits of Home Care in Canada 2008*, p. 103.
- 16 Ibid., p 60.
- 17 Ibid., p. 172.



- 18 Ibid., p. 23.
- 19 Ibid., p. 40.
- 20 Ibid., p. 200.
- 21 Ibid., p. 118.
- 22 Ibid., p. 156.
- 23 Ibid., p. 138.
- 24 Ibid., pp. 215–216.
- 25 Ibid., p. 186.
- 26 Ostry, *Change and Continuity in Canada's Health Care System*, p. 231.
- 27 Ibid., p. 230.
- 28 Ibid.
- 29 First Ministers of Canada, *First Ministers' Accord on Health Care Renewal*, 2003, pp. 3–4.
- 30 Gisèle Carrière, "Seniors' Use of Home Care," *Health Reports* 17,4, p. 43.
- 31 Ibid.
- 32 Statistics Canada. "Participation and Activity Limitation Survey," *The Daily*, Dec. 3, 2007, p. 3.
- 33 Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians — The Federal Role, Final Report. Volume Six: Recommendations for Reform*, Oct. 2002, p. 149.
- 34 Kathryn Wilkins, "Government-subsidized Home Care." *Health Reports* 17,4, Oct. 2006.
- 35 Canadian Home Care Association website facts. The 1995 data come from the Canadian Institute for Health Information and the 2006 data from the Canadian Home Care Association.
- 36 Pollara, *Health Care in Canada: 10th Anniversary Survey Results*. Part 1, Slide 198.
- 37 Ibid.
- 38 Statistics Canada, "2006 Census: Age and Sex," *The Daily*, July 17, 2007.
- 39 Peter Sargious, *Chronic Disease Prevention and Management*. Part of Sharing Insights: Primary Health Care Transition Fund Synthesis Series, 2007, p. 1.
- 40 Health Council of Canada. *Why Health Care Renewal Matters: Learning from Canadians with Chronic Health Conditions*. Toronto: Health Council of Canada, 2007, p. 12.
- 41 Jonathan Gray, "Home Care in Ontario: The Case for Copayments," *Health Law Journal* 8, 186, 2000.
- 42 Wilkins, *Health Reports*.
- 43 Health Council of Canada, *Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada*, 2008, p. 36.
- 44 Canadian Institute for Health Information, "Government home care spending reaches \$3.4 billion in 2003–2004 — CIHI study is the first of its kind to look at government spending on health care," News release, March 22, 2007.
- 45 Ibid.
- 46 Health Council of Canada, *Fixing the Foundation*, p. 30.
- 47 Canadian Institute for Health Information, "Wide variation in public/private funding of health care services," Press release, Sept. 27, 2005.
- 48 Janet Fast and Judith Frederick came up with the figure of \$5 billion in their 1999 paper "Informal Caregiving: Is It Really Cheaper? This amount was based on 1996 data. Philippe Le Goff, in his 2002 report *Home Care Sector in Canada: Economic Problems*, estimates that the \$5 billion would be more like \$6 billion; six years later, it would be higher still.
- 49 Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care, Final Project Report*, April 2001, p. 1.
- 50 Canadian Home Care Association, "Home Care for Children with Special Needs: An Environmental Scan Across Canadian Provinces and Territories" (CD-ROM), 2006, p. 6.
- 51 Ibid., p. 7.
- 52 Ibid., p. 5.
- 53 Ibid., p. 5.
- 54 Ibid., p. 4.
- 55 Ibid., p. 4.
- 56 Ibid., p. 5.
- 57 Ibid., p. 110.
- 58 Ibid., p. 8.

- 59 Ibid., p. 6.
- 60 Quality End-of-Life Care Coalition of Canada, "New QELCCC Report: Provinces and Territories Making Progress in Providing Palliative Home Care but Inequalities in Access Still Exist," *AVISO 56* (Summer 2008), p. 1.
- 61 Carole Lafontaine, President of the National Aboriginal Health Organization, Presentation to the Senate Standing Committee on Aging, Nov. 27, 2006.
- 62 Please note that Veterans Affairs probably delivers home care services to First Nations and Inuit veterans. As yet, we have received no response to a query on this subject from Veterans Affairs.
- 63 Carole Lafontaine, Presentation to the Senate Standing Committee on Aging.
- 64 Canadian Home Care Association, *Portraits of Home Care in Canada 2008*, p. 234.
- 65 Indian and Northern Affairs Canada, "INAC's Adult Care Program."
- 66 Canadian Home Care Association, *Portraits of Home Care in Canada 2008*, p. 53.
- 67 Shapiro, *Home Care*, p. 10.
- 68 Health Council of Canada, *Fixing the Foundation*, p. 9.
- 69 Health Council of Canada, *Rekindling Reform: Health Care Renewal in Canada, 2003–2008*, p. 17.
- 70 Canadian Home Care Association, *The Delivery of Home Care Services in Rural and Remote Communities in Canada*, p. 8.
- 71 Demers et al., "Comparison of Provincial Prescription Drug Plans and the Impact on Patients' Annual Drug Expenditures," *Canadian Medical Association Journal* 178, 4, Feb. 12, 2008, p. 409.
- 72 Canadian Home Care Association, *Integration Through Information Communication Technology in Home Care: Survey Findings*, Jan. 2008, p. 16.
- 73 Commonwealth Fund, *2006 International Survey of Primary Care Doctors*.
- 74 Canadian Home Care Association, *Portraits of Home Care in Canada 2008*, p. 17.
- 75 Ibid., p. 51.
- 76 Ibid., p. 71.
- 77 Ibid., p. 129.
- 78 Ibid., p. 148.
- 79 Ibid., p. 164.
- 80 Ibid., p. xvii.
- 81 Ibid., p. 193.
- 82 Ibid., p. 223.
- 83 Ibid., p. 208.
- 84 François Béland, Howard Bergman and Paule Lebel. "SIPA. An Integrated System of Care for Frail Elderly Persons." Presentation at the Canadian Research Network for Care in the Community conference, Toronto, Ontario, Oct. 23, 2006.
- 85 Health Canada, Primary Health Care Transition Fund, Initiative Fact Sheet: Prince Edward Island. Accessed March 30, 2009, at: [http://www.apps.hc-sc.gc.ca/hcs-sss/phctf-fassp.nsf/1kAttachments/3AC12830CC235BD48525728E006ACED1/\\$File/31E_FS_PEL.pdf](http://www.apps.hc-sc.gc.ca/hcs-sss/phctf-fassp.nsf/1kAttachments/3AC12830CC235BD48525728E006ACED1/$File/31E_FS_PEL.pdf).
- 86 Janet Lum, "Integrated Care," Presentation at Look Globally, Act Locally: Integrating Care in the Community for Vulnerable Populations conference, Toronto, Ontario, Oct. 20, 2008.
- 87 Christel A. Woodward, "Home Care in Australia, Some Lessons for Canada," McMaster University Centre for Health Economics and Policy Analysis (CHEPA) Working Paper 04-02, July 2004.
- 88 Parliament of Australia, "Caring for the Elderly: An Overview of Aged Care Support and Services in Australia," E-brief dated Feb. 27, 2003, updated April 30, 2003.
- 89 Woodward, "Home Care in Australia, Some Lessons for Canada."
- 90 Ibid.
- 91 Laurence G. Thompson, "Clear Goals, Solid Evidence, Integrated Systems, Realistic Roles," *HealthcarePapers* 1,4, 2000, p. 62.
- 92 A quote from Hollander, in Marcus J. Hollander and Angela Tessaro, *Evaluation of the Maintenance and Preventive Function of Home Care, Final Report*, March 2001.
- 93 Health Canada notes: "The HSURC (2000) study examined a cohort of 26,490 seniors over a period of eight years. Approximately 36% of the participants (9,524) received preventive home care and 9% of the participants (2,484) were in seniors housing. The study found that 50% of the individuals receiving preventive home care were more likely to lose their independence or die than those not receiving this service. In addition, costs for clients on preventive home care were three times higher than for clients not receiving this service. The findings need to be interpreted cautiously, however, as there were a number of methodological issues that could have affected the results (HSURC, 2000)." From Health Canada website: http://www.hc-sc.gc.ca/fniah-spnia/pubs/services/_home-domicile/2008_assess-lit-exam-doc/05-cost-cout-eng.php.
- 94 Marcus Hollander, *Unfinished Business: The Case for Chronic Home Care Services, A Policy Paper*. Victoria: Hollander Analytical Services, August 2003 (updated 2004).

- 95 Shapiro, *Home Care*, p. 1.
- 96 Ostry, *Change and Continuity in Canada's Health Care System*, p. 234.
- 97 Philip Jacobs (Hollander Analytical Services), *Substudy 9: Costs of Acute Care Services Compared to Home Care Services, Executive Summary*.
- 98 Health Canada, *Primary Health Care Transition Fund, Summary of Initiatives*, Final Edition, March 2007, pp. 111–112.
- 99 Hollander Analytical Services, *Home Care Program Review*, Feb. 2006, p. ii.
- 100 Canadian Research Network for Care in the Community, "The Balance of Care," In Focus fact sheet.
- 101 Miller Jo Ann, Marcus Hollander and Margaret MacAdam, "The Continuing Care Research Project for Veterans Affairs Canada and the Government of Ontario," Draft report, p. i.
- 102 M. Markle-Reid, G. Browne, R. Weir, A. Gafini, J. Roberts and S. Henderson, "Seniors at Risk: The Association Between the Six-Month Use of Publicly Funded Home Support Services and Quality of Life and Use of Health Services for Older People," *Canadian Journal on Aging* 27, 2, 2008, pp. 207–224.
- 103 *Ibid.*, p. 7.
- 104 *Ibid.*, p. 1.
- 105 Derek Wanless, *Securing Good Care for Older People*, London: King's Fund, 2006, p. xxiii.
- 106 *Ibid.*, p. xxix.
- 107 *Ibid.*, p. xxx.
- 108 *Ibid.*, p. 284.
- 109 Réjean Hébert, Pierre Durand, and André Tourigny, "Frail Elderly Patients: New Model for Integrated Service Delivery," *Canadian Family Physician* 49, Aug. 2003, p. 996.
- 110 *Ibid.*, p. 996.
- 111 Ontario Human Rights Commission, "Time for Action: Advancing Human Rights for Older Ontarians."
- 112 Canadian Home Care Association and Human Resources Development Canada, *Canadian Home Care Human Resources Study, Synthesis Report*, Table 8, "Estimates of the Number of Formal, Paid Care Providers in the Home Sector," p. 14.
- 113 *Ibid.*, p. 15.
- 114 See Canadian Home Care Association and Human Resources Development Canada, *Canadian Home Care Human Resources Study, Phase 1 Highlights – Setting the Stage: What Shapes the Home Care Labour Market*.
- 115 Carol Kushner, Patricia Baranek and Marion Dewar, *Home Care: Change We Need*, Nov. 17, 2008, pp. 26–27.
- 116 *Ibid.*, p. 6.
- 117 Marika Morris et al., "The Changing Nature of Home Care and Its Impact on Women's Vulnerability to Poverty," Nov. 1999, p. 49.
- 118 Canadian Union of Public Employees, "Hamilton home care sector suffers loss of experience and continuity through competitive bidding," News release, Dec. 18, 2007.
- 119 Margaret Denton et al., "Market-Modelled Home Care: Impact on Job Satisfaction and Propensity to Leave," *Canadian Public Policy* 33, Special edition, 2007, pp. 81–99.
- 120 Isik U. Zeytinoglu and Margaret Denton, *Satisfied Workers, Retained Workers: Effects of Work and Work Environment on Homecare Workers' Job Satisfaction, Stress, Physical Health, and Retention. Key Implications for Decision Makers*.
- 121 Canadian Home Care Association and Human Resources Development Canada, *Canadian Home Care Human Resources Study (2003)*, Retrieved July 28, 2008, at: http://www.cha.ca/documents/pa/Home_Care_HR_study.pdf.
- 122 Kushner, Baranek and Dewar, *Home Care: Change We Need*, p. 51.
- 123 *Ibid.*, p. 47.
- 124 Zeytinoglu and Denton, *Satisfied Workers, Retained Workers*.
- 125 Pollara, *Health Care in Canada: 10th Anniversary Results, Part 1*, Dec. 2007, Slide 210.
- 126 Health Council of Canada, *Fixing the Foundation*. "Foreword."
- 127 Pollara, *Health Care in Canada: 10th Anniversary Survey Results*, Slide 211.
- 128 Health Canada, "Continuing Care in First Nations and Inuit Communities: Evidence from the Research."
- 129 Norm O'Rourke et al., "Recurrent Depressive Symptomatology and Physical Health: A 10-Year Study of Informal Caregivers of Persons with Dementia," *The Canadian Journal of Psychiatry*, 52, 7, July 2007.
- 130 Canadian Institute for Health Information, "Home Care Reporting System," Nov. 2006.
- 131 Pollara, *Health Care in Canada: 10th Anniversary Survey Results*, Slide 214.
- 132 University of Alberta, "Monetizing the Costs to Caregivers," Hidden Costs, Invisible Contributions Research Program, PowerPoint slides.
- 133 The Centre for Spatial Economics, *The Economic Cost of Wait Times in Canada*, June 2006 (updated Jan. 2008).
- 134 *Ibid.*, p. 3.

- 135 Ibid., p. 36.
- 136 University of Alberta, "Family/Friend Caregiving in Canada: Gender Matters," Research on Aging Policies and Practice (RAPP), Fact sheet, Oct. 2007.
- 137 Kelly Cranswick and Donna Dosman, "Eldercare: What We Know Today," *Canadian Social Trends*, Statistics Canada Catalogue no. 11-008, Oct. 21, 2008.
- 138 Janet Fast, "Caregiving: A Fact of Life," *Transition Magazine* 35,2, Summer 2005.
- 139 Janet E. Fast, B. Higham, N. Keating, D. Dosman, and J. Eales, *Family/Friend Caregiving and Its Consequences: Implications for the Compassionate Care Benefit Program*, Final Report to Human Resources and Skills Development Canada, Audit and Evaluation Directorate, pp. 28–29.
- 140 Alzheimer Society, Alzheimer statistics. <http://www.alzheimer.ca/english/disease/stats-people.htm>.
- 141 Fast et al., *Family/Friend Caregiving and Its Consequences*.
- 142 Ibid., pp. 31–32.
- 143 Interestingly, in Ireland, the respite care grant was increased from 200 pounds to 1700 per year in respect of each care recipient. From Eilish O'Regan, "Irish Survey Shows 161,000 Carers Under Threat," *Family Caregiver*, Oct. 2008, p. 10. Clearly, some countries are recognizing the importance of respite care for the caregiver.
- 144 Victorian Order of Nurses, "In the caring hands of your neighbour: VON expands neighbours helping neighbours program," News release, June 10, 2008.
- 145 Canadian Caregiver Coalition webpage, "Who We Are." Retrieved Jan. 27, 2009, at: <http://www.ccc-ccan.ca/content.php?sec=1>.
- 146 Carers U.K. webpage, "Carers Rights at Work." Retrieved April 30, 2008, at: <http://www.carersuk.org/Information/Workandcaring/Carersrightsatwork>.
- 147 A quote from Boise, Heagerty and Eskanazi (1996) as quoted in Miriam J. Stewart and Lynn Langille, "A Framework for Social Support Assessment and Intervention in the Context of Chronic Conditions and Caregiving," Miriam J. Stewart (ed.) *Chronic Conditions and Caregiving in Canada: Social Support Strategies*, p. 5.
- 148 CARP (Malcolm Anderson and Karen Parent, Principal Investigators), *Putting a Face on Home Care: CARP's Report on Home Care in Canada, 1999*.
- 149 Canadian Mental Health Association, *Home Care and People with Psychiatric Disabilities, Needs and Issues: A National Evaluation*, Oct. 2000, p. 8.
- 150 Health Council of Canada, *Fixing the Foundation*, p. 36.
- 151 Ibid.
- 152 Hollander Analytical Services, *Analysis of Interfaces Along the Continuum of Care Final Report: "The Third Way,"* p. 25.
- 153 Canadian Institute for Health Information, *cihidirectionsics*, Fall 2007, p. 5.
- 154 Statistics Canada, "Deaths," *The Daily*, Jan. 14, 2008.
- 155 The Standing Senate Committee on Social Affairs, Science and Technology, *Quality End-of-Life Care: The Right of Every Canadian*, Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, Final Report, June 2000.
- 156 Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada*, 2007, p. xi.
- 157 No author, *Report to the Annual Premiers' Conference*, August 2002.
- 158 Karen Parent and Malcolm Anderson, "Developing a Home Care System by Design," *HealthcarePapers* 1,4, 2000, p. 52.
- 159 Canadian Home Care Association, *Integration Through Information Communication Technology for Home Care in Canada*, 2008, p. 5.
- 160 Laurence G. Thompson, "Clear Goals, Solid Evidence, Integrated Systems, Realistic Roles," p. 65.
- 161 Hollander, Marcus J., *Unfinished Business*, p. 8.
- 162 Liberal Task Force on Seniors, *Liberal Task Force Report*, p. 15.
- 163 Shapiro, *Home Care*, p. 10.
- 164 Health Council of Canada, *Fixing the Foundation*, p. 37.
- 165 Canadian Healthcare Association, Pre-budget brief, Sept. 2006, p. 5.
- 166 Shapiro, *Home Care*, p. 18.
- 167 Demers et al., "Comparison of Provincial Prescription Drug Plans and the Impact on Patients' Annual Drug Expenditures," *Canadian Medical Association Journal* 178,4, Feb. 12, 2008, p. 409.
- 168 Canadian Healthcare Association, *A Responsive, Sustainable, Publicly Funded Health System in Canada: The Art of the Possible*, p. 18.
- 169 François Béland and Howard Bergman, "Home Care, Continuing Care and Medicare: A Canadian Model or Innovative Models for Canadians," *HealthcarePapers* 1,4, 2000, p. 44.
- 170 Ibid., p. 19.
- 171 Shapiro, *Home Care*, p. 20.

- 172 Liberal Task Force on Seniors, p. 13.
- 173 Canadian Association for Community Care and the Canadian Home Care Association, "Sustaining Canada's Health Care System: The Role of Home and Community Care."
- 174 Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians — The Federal Role, Final Report. Volume Six: Recommendations for Reform*, Oct. 2002, p. 260.
- 175 *Ibid.*, pp. 261–262.
- 176 Shapiro, *Home Care*, p. 18.
- 177 Canadian Healthcare Association, *Home, Community and Long-Term Care — CHA's Pre-budget Recommendations on Home and Long-term Care*. Oct. 17–19, 2007, pp. 27–28.
- 178 Canadian Healthcare Association, "Policy Recommendations Regarding Issues Addressed by the National Pharmaceuticals Strategy: Broad Policy Positions," June 2006, p. 9.
- 179 Shapiro, *Home Care*, p. 18.
- 180 Kushner, Baranek and Dewar, *Home Care: Change We Need*, p. 40.
- 181 Frieda Waisberg (speaking on behalf of Frieda Waisberg, Audrey Laporte, Carey Levinton, Raisa Deber, Linda O'Brien- Pallas, Andrea Baumann, and Kanecy Onate), "The Importance of Nurse Employment Categories in Determining Exit Rates from Nursing," <http://teamgrant.ca/Posterandpress/2008sym/6.2%20Frieda.pdf>. Presentation by the Canadian Institutes of Health Research (CIHR) Team in Community Care and Health Human Resources, at the Care in the Community and Health Human Resources symposium, Ryerson University, Toronto, Ontario, March 18, 2008. Please note that the presentation refers to Ontario data only.
- 182 Brenda Gamble, "Employment Patterns Among Ontario's Allied Health Professionals," Presentation at the Care in the Community and Health Human Resources symposium, Ryerson University, Toronto, Ontario, March 18, 2008. Please note that the presentation refers to Ontario data only.
- 183 All from Canadian Home Care Association and Human Resources Development Canada, *Canadian Home Care Human Resources Study Technical Report*, 2003, pp. 109–113.
- 184 From Health Professions Regulatory Advisory Council Sept. 2006 letter to the Ontario Ministry of Health and Long- Term Care in respect of Personal Support Workers, Public release, June 27, 2006.
- 185 Canadian Healthcare Association, *A Responsive, Sustainable, Publicly Funded Health System in Canada: The Art of the Possible*, Feb. 2002, p. 13.
- 186 *Medical News Today*, April 2, 2008.
- 187 Canadian Healthcare Association, *A Responsive, Sustainable, Publicly Funded Health System in Canada*, p. 14.
- 188 Canadian Healthcare Association, *Pre-budget brief*, September 2006 and August 2007.
- 189 Canadian Healthcare Association, *A Responsive, Sustainable, Publicly Funded Health System in Canada*, p. 14.
- 190 Health Council of Canada, *Fixing the Foundation*, p. 37.
- 191 Canadian Healthcare Association, Briefing Documents, Board of Directors Meeting, Section 8.5, June 9, 2007.
- 192 Shapiro, *Home Care*, p. 19.
- 193 Hollander, Marcus J., *Unfinished Business*, p. 8.

Bibliography

- Alcock, Denise. "Are We Finally Ready for a Canadian Model for Home Care?" *HealthcarePapers* 1,4 (Fall 2000): 74–80.
- Alzheimer Society. Alzheimer statistics. Retrieved June 13, 2008, at: <http://www.alzheimer.ca/english/disease/stats-people.htm>.
- Anderson, Malcolm and Karen Parent. "Care in the Home: Public Responsibility — Private Roles?" Paper prepared for the Dialogue on Health Reform, June 2000.
- Assembly of First Nations. *Sustaining the Caregiving Cycle: First Nations People and Aging. A Report from the Assembly of First Nations to the Special Senate Committee on Aging*. May 2007. Retrieved May 8, 2008, at: <http://www.afn.ca/misc/SCC.pdf>.
- Baranek, Patricia M., Raisa B. Deber and A. Paul Williams. *Almost Home: Reforming Home and Community Care in Ontario*. (Toronto: University of Toronto Press, 2004).
- Barrett, Peter. "Rethinking Medicare: Response from the Canadian Medical Association." *HealthcarePapers* 1,4 (Fall 2000): 115–120.
- Béland, François and Howard Bergman. "Home Care, Continuing Care and Medicare: A Canadian Model or Innovative Models for Canadians?" *HealthcarePapers* 1,4 (Fall 2000): 38–46.
- Béland, François, Howard Bergman and Paule Lebel. "SIPA. An Integrated System of Care for Frail Elderly Persons." Presentation at the Canadian Research Network for Care in the Community conference. Toronto. October 23, 2006. Accessed March 26, 2009, at: <http://www.ryerson.ca/crncc/events/presentations/Francois%20Beland%20--%20SIPA%20an%20integrated%20system%20of%20care%20for%20frail%20elderly%20persons.pdf>.
- Black, Laurene. "The Role of the Health Care Aide in a High Needs Pediatric Population in the Community." Presentation at the symposium Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada, held February 20, 2007. Retrieved March 4, 2008, at: <http://www.crncc.ca/events/download/LaureneBlack-February20thpresentation.pdf>.
- Bosco, Carmella, Philip Ellison, Ivy Oandasan, A. Paul Williams and Anne Wojtak. "Two Sectors Meet: Primary Health Care and Home Care Join Forces to Better Serve Canadians." Background Paper on the Integration of Primary Health Care and Home Care Services in Canada. (Ottawa: Health Canada, March 7, 2006).
- Braedley, Susan. "Accidental Care: Masculinity, Care and Politics." Doctoral Dissertation, York University 2008. Read in draft form, September 2, 2008.
- Braedley, Susan. "Accidental Care: Masculinity and Neoliberalism at Work," in Braedley, S. and M. Luxton (eds.). *Penetrating Neoliberalism*. (Montreal: McGill Queens, 2009).
- British Columbia Institute of Technology. "Home Monitoring Technologies in the Community/Home Care Environment." March 2006. Retrieved April 5, 2008, at: <http://www.winbc.org/files/PDF/Resources/HomeMonitorIndustryPullStudy06.pdf>.
- Campbell, Bruce and Greg Marchildon (eds.). *Medicare Facts: Myths, Problems and Promise*. (Toronto: James Lorimer and Co., 2007).



- Canadian Association for Community Care and the Canadian Home Care Association. "Sustaining Canada's Health Care System: The Role of Home and Community Care." N.d.
- Canadian Broadcasting Corporation. "Province Halts Bid for Home Care Services." January 23, 2008. Retrieved January 23, 2008, at: www.cbc.ca/canada/ottawa/story/2008/01/23/home-care.html.
- Canadian Caregiver Coalition. "A Proposition on Family Caregiving." www.ccc-ccan.ca.
- Canadian Caregiver Coalition. "A Framework for a Canadian Caregiving Strategy." December 1, 2008.
- Canadian Healthcare Association. *The Private-Public Mix in the Funding and Delivery of Health Services in Canada*. (Ottawa: Canadian Healthcare Association, 2001).
- Canadian Healthcare Association. *A Responsive, Sustainable, Publicly Funded Health System in Canada: The Art of the Possible*. (Ottawa: Canadian Healthcare Association, 2002).
- Canadian Healthcare Association. *Stitching the Patchwork Quilt Together: Facility-Based Long-Term Care Within Continuing Care — Realities and Recommendations*. (Ottawa: Canadian Healthcare Association, 2004).
- Canadian Healthcare Association. "Policy Recommendations Regarding Issues Addressed by the National Pharmaceuticals Strategy: Broad Policy Positions." June 2006.
- Canadian Healthcare Association. Pre-budget Brief. September 2006, and August 2007.
- Canadian Healthcare Association. Briefing Documents, Board of Directors Meeting. June 9, 2007.
- Canadian Healthcare Association. *Home, Community and Long-Term Care — CHA's Pre-budget Recommendations on Home and Long-term Care*. Report of the Department of Policy and Communications to the Board of Directors. October 17–19, 2007.
- Canadian Healthcare Association. "Presentation to the Senate Committee on Aging." (Ottawa. December 10, 2007).
- Canadian Home Care Association. *Strengthening Home Care: A Call for Action*. May 2001.
- Canadian Home Care Association. *Home Care & Palliative Care: Recommendations to Increase Awareness, Access and Integration; A Review of Provincial/Territorial Programs*. January 2003.
- Canadian Home Care Association. *Recommendations to Increase Awareness, Access and Integration: A Review of Provincial/Territorial Programs*. March 2003.
- Canadian Home Care Association. *Portraits of Home Care: A Picture of Progress and Innovation*. 2003.
- Canadian Home Care Association. *Realizing the Potential of Home Care: A Movement from Statements to Action*. July 2004.
- Canadian Home Care Association. *Home Care Case Management: Invitational Roundtable, March 3–4, 2005. Summary of Proceedings*. (Ottawa: Health Canada, 2005). <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-cas-mgmt-gest/index-eng.php>.
- Canadian Home Care Association. "Home Care for Children with Special Needs: An Environmental Scan Across Canadian Provinces and Territories." CD-ROM. September 2006.
- Canadian Home Care Association. *The Delivery of Home Care Services in Rural and Remote Communities in Canada: Identifying Service Gaps and Examining Innovative Practice*. November 2006.
- Canadian Home Care Association. "The Integral Role of Home Care in Improving Access to Care." January 2007. www.cdnhomocare.ca.
- Canadian Home Care Association. *Implementing Case Management as a Strategy for Systems Integration. Experiences from the CHCA National Partnership Project*. August 2007. <http://www.cdnhomocare.ca/media.php?mid=1557>.
- Canadian Home Care Association. "Results of the Canadian Home Care Association ICT Survey, December 2007:" <http://www.cdnhomocare.ca/media.php?mid=1655>.
- Canadian Home Care Association. *Integration Through Information Communication Technology in Home Care: Survey Findings*. January 2008. Retrieved January 14, 2008, at: <http://www.cdnhomocare.ca/media.php?mid=1655>.
- Canadian Home Care Association. *Integration Through Information Communication Technology for Home Care in Canada*. (Ottawa: Canadian Home Care Association, March 2008).
- Canadian Home Care Association. *Portraits of Home Care in Canada 2008*. (Ottawa: Canadian Home Care Association, March 2008).
- Canadian Home Care Association and the Canadian Association for Community Care. "Sustaining Canada's Health Care System: The Role of Home and Community Care." N.d.
- Canadian Home Care Association and Human Resources Development Canada. *Canadian Home Care Human Resources Study, Phase 1 Highlights – Setting the Stage: What Shapes the Home Care Labour Market*. December 4, 2001. www.cdnhomocare.ca
- Canadian Home Care Association and Human Resources Development Canada. *Canadian Home Care Human Resources Study Synthesis Report*. October 2003. www.cdnhomocare.ca
- Canadian Home Care Association and Human Resources Development Canada. *Canadian Home Care Human Resources Study Technical Report*. December 2003. www.cdnhomocare.ca.
- Canadian Home Care Association and Human Resources Development Canada, *Canadian Home Care Human Resources Study (2003)*, Retrieved July 28, 2008, at: http://www.cha.ca/documents/pa/Home_Care_HR_study.pdf.
- Canadian Hospice Palliative Care Association. *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home*. (Ottawa: Canadian Hospice Palliative Care Association, December 2006).
- Canadian Institute for Health Information. *Development of National Indicators and Reports for Home Care. Final Project Report*. (Ottawa: Canadian Institute for Health Information, April 2001).

- Canadian Institute for Health Information. *Development of National Indicators and Reports for Home and Community Care. Final Project Report.* (Ottawa: Canadian Institute for Health Information, 2004).
- Canadian Institute for Health Information. *Proceedings of the Home Care Summit 2003.* (Ottawa: Canadian Institute for Health Information, 2004).
- Canadian Institute for Health Information. "Home Care Roadmap Indicators: Indicator Descriptions." July 2004. (Ottawa: Canadian Institute for Health Information, 2004).
- Canadian Institute for Health Information. "Wide variation in public/private funding of health care services." Press release, September 27, 2005.
- Canadian Institute for Health Information. "Home Care Reporting System." (Ottawa: Canadian Institute for Health Information, November 2006).
- Canadian Institute for Health Information. *Health Care Use at the End of Life in Western Canada.* (Ottawa: Canadian Institute for Health Information, 2007).
- Canadian Institute for Health Information. "Public-Sector Expenditures and Utilization of Home Care Services in Canada." (Ottawa: Canadian Institute for Health Information, 2007).
- Canadian Institute for Health Information. "Government home care spending reaches \$3.4 billion in 2003–2004 — CIHI study is the first of its kind to look at government spending on health care." News release, March 22, 2007.
- Canadian Institute for Health Information. *cihidirections*, Fall 2007.
- Canadian Institute for Health Information. *National Health Expenditure Trends, 1975–2008.* (Ottawa: Canadian Institute for Health Information, 2008).
- Canadian Institute for Health Information and Statistics Canada. *Health Care in Canada: A First Annual Report.* (Ottawa: Canadian Institute for Health Information, 2000).
- Canadian Intergovernmental Conference Secretariat. "Provinces pave the way for the future of health care." News release 850-085/004. Provincial–Territorial Premiers Meeting. Vancouver, British Columbia. January 24–25, 2002. http://www.scics.gc.ca/cinfo02/850085004_e.html.
- Canadian Mental Health Association. *Home Care and People with Psychiatric Disabilities, Needs and Issues: A National Evaluation.* October 2000.
- Canadian Nurses Association. *A National Approach to Home and Community Care: Through the Lens of the Canada Health Act.* (Ottawa: Canadian Nurses Association, March 2000).
- Canadian Research Network for Care in the Community. "Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada." February 20, 2007. <http://www.crnc.ca/events/2007-02-CRNCC-CYHN.html>.
- Canadian Research Network for Care in the Community. "The Balance of Care." In Focus fact sheet. <http://www.crnc.ca/knowledge/factsheets/download/InFocus-TheBalanceofCareApr302007.pdf>.
- Canadian Union of Public Employees. "Ontario turns home care services into for-profit bonanza." Press release, December 13, 2007. http://cupe.ca/p3alertdec2007/Province_turns_home_.
- Canadian Union of Public Employees. "Hamilton home care sector suffers loss of experience and continuity through competitive bidding." News release, December 18, 2007.
- Capital Health. "Capital Health Home Care Children's Services wins national award." News release, August 15, 2007. Accessed March 26, 2009, at http://www.capitalhealth.ca/NewsAndEvents/Features/2007/Home_Care_Childrens_Services_award.htm.
- CARP (Malcolm Anderson and Karen Parent, Principal Investigators). *Putting a Face on Home Care: CARP's Report on Home Care in Canada, 1999.* Retrieved February 8, 2008, at: <http://chspr.queensu.ca/downloads/Reports/Putting%20a%20Face%20on%20Home%20Care%201999.pdf>.
- Carrière, Gisèle. "Seniors' Use of Home Care." *Health Reports* 17,4 (October 2006). Ottawa: Statistics Canada, Catalogue No. 82-003.
- Centre for Spatial Economics. *The Economic Cost of Wait Times in Canada.* June 2006 (updated January 2008).
- The Change Foundation. *Facing the Facts: Homecare in Ontario, User Profile & Areas for Improvement.* N.d. http://www.changefoundation.ca/docs/FacingFacts_HomeCareOnt_3.pdf.
- Chappell, Neena. "Maintaining the Integrity of Home Care." *HealthcarePapers* 1,4 (Fall 2000): 91–96.
- Chessie, Kelly (Health Services Utilization and Research Commission). "No Evidence Found That Preventive Home Care Improves Seniors' Health Outcomes: Study." *A Closer Look* (Summer 2000): 1–2.
- Citizens for Mental Health. *Caregiver Support and Mental Health.* http://www.cmha.ca/data/1/rec_docs/194_caregiver_2.pdf.
- Closson, Tom. As quoted in *Health Edition* 12,9 (2008).
- Commission on the Future of Health Care in Canada, Commissioner Roy J. Romanow. *Shaping the Future of Health Care. Interim Report.* (Ottawa: Queen's Printer, February 2002).
- Commonwealth Fund. *2006 International Survey of Primary Care Doctors.* Retrieved January 26, 2008, at: http://www.cmf.org/usr_doc/topline_results_2006_IHPSurvey2.pdf.
- Côté, André and Graham Fox. *The Future of Homecare in Canada: Roundtable Outcomes and Recommendations for the Future.* (Ottawa: Public Policy Forum, March 2007).

- Coyte, Peter C. "Home Care: Potentials and Problems." Presentation at Diagnostics and Solutions: Building Consensus for Health Care Reform in Canada, February 14–16, 2002. Retrieved February 8, 2008, at: www.hcerc.org.
- Coyte, Peter C. *Home and Community Care in Canada: Passing the Buck*. (Toronto: Author, 2000).
- Coyte, Peter C. *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*. www.homecarestudy.com.
- Cranswick, Kelly and Donna Dosman. "Eldercare: What We Know Today." *Canadian Social Trends*. Statistics Canada, Catalogue No. 11–008, October 21, 2008.
- Cutler, Judy and Bill Gleberzon (CARP, Canada's Association for the Fifty-Plus). "The Silent Victim in a Silent System: Elder Abuse of Informal Caregivers." Address in Toronto, Ontario. n.d. Accessed March 30, 2009, at: <http://www.carp.ca/advocacy/adv-article-display.cfm?documentID=1396>.
- Deber, Raisa, Marcus J. Hollander and Philip Jacobs. "Models of Funding and Reimbursement in Health Care: A Conceptual Framework." *Canadian Public Administration* 51,3 (September 2008): 381–405.
- Decter, Michael. "The Evolution of Canadian Health Care: Poetry, Policy and Prospects." Notes for the 2005 Gow Lecture.
- Demers, Virginie et al. "Comparison of Provincial Prescription Drug Plans and the Impact on Patients' Annual Drug Expenditures." *Canadian Medical Association Journal* 178,4 (February 12, 2008): 405–409.
- Denton, Margaret, Isik Urla Zeytinoglu, Sharon Davies and Danielle Hunter. "The Impact of Implementing Managed Competition on Home Care Workers' Turnover Decisions." *Healthcare Policy* 1,4 (2006): 106–123.
- Denton, Margaret, Isik Zeytinoglu, Karen Kusch and Sharon Davies. "Market-Modelled Home Care: Impact on Job Satisfaction and Propensity to Leave." *Canadian Public Policy* 33 (special edition, 2007): 81–99.
- Department of Finance. "Federal Transfers in Support of the 2000/2003/2004 First Ministers' Accords." Accessed March 26, 2009, at: <http://www.fin.gc.ca/fedprov/fmAcc-eng.asp>
- Doran, Diane, Jennie Pickard and Janet Harris. "The Relationship Between Characteristics of Home Care Nursing Service Contracts Under Managed Competition and Continuity of Care and Client Outcomes: Evidence from Ontario." *Healthcare Policy* 2,4 (2007): 97–112.
- Eales, Jacquie, Norah Keating and Janet Fast. "Analysis of the Impact of Federal, Provincial and Regional Policies on the Economic Well-Being of Informal Caregivers of Frail Seniors." August 2, 2001.
- Fast, Janet. "Caregiving: A Fact of Life." *Transition Magazine* 35,2 (Summer 2005).
- Fast, Janet and Judith Frederick. "Informal Caregiving: Is It Really Cheaper?" Paper presented at the International Association of Time Use Researchers Conference, Colchester, England, October 6–8, 1999. Retrieved April 6, 2008, at: <http://www.iser.essex.ac.uk/conferences/iatur/1999/pdf/paper4.pdf>.
- Fast, Janet, Jacquie Eales, Norah Keating. *Economic Impact of Health Income Security and Labour Policies on Informal Care Givers of Frail Seniors*. (Ottawa: Status of Women 2001).
- Fast, Janet. E., B. Higham, N. Keating, D. Dosman and J. Eales. *Family/Friend Caregiving and Its Consequences: Implications for the Compassionate Care Benefit Program*. Final Report to Human Resources and Skills Development Canada, Audit and Evaluation Directorate. (Edmonton: Authors, November 25, 2005).
- Federal-Provincial-Territorial (FPT) Advisory Committee on Health Services (ACHS) Working Group on Continuing Care. *Technical Report 4: Case Study on Resource Allocation in Home Care—Saskatchewan and Nova Scotia*. May 2000. Part of the series The Identification and Analysis of Incentives and Disincentives and Cost-Effectiveness of Various Funding Approaches for Continuing Care.
- First Ministers of Canada. *First Ministers' Accord on Health Care Renewal*. 2003.
- Fooks, Cathy and Steven Lewis. "Romanow and Beyond: A Primer on Health Reform Issues in Canada." Discussion Paper No. H/05 Health Network. November 2002.
- FPT Working Group on Home Care, A Working Group of the FPT Subcommittee on Long-Term Care. *Report on Home Care*. (Ottawa: Health Canada, 1990).
- Gamble, Brenda. "Employment Patterns Among Ontario's Allied Health Professionals." Presentation at the 2008 symposium Care in the Community and Health Human Resources, Ryerson University, Toronto, Ontario, March 18, 2008. <http://teamgrant.ca/Posterandpress/2008sym/6.3%20Brenda.pdf>
- The Globe and Mail*. "Rotman Award Plays Key Role in Pediatric Home Care." Leadership in Children's Health: An Information Feature to The Globe and Mail, November 29, 2006. P. E3. Retrieved April 1, 2008, at: http://www.sickkidsfoundation.com/news/downloads/globeandmail_nov27.pdf.
- Goldner, Elliot M. *Mental Health*. Sharing the Learning: The Health Transition Fund Synthesis Series. (Ottawa: Health Canada, 2002).
- Government of Australia. "National Respite for Carers Programs and Other Australian Government's Support for Carers." Retrieved March 14, 2008, at: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-qcoa-05info.htm>.
- Government of Australia, Department of Health and Aging. "Help Staying at Home." <http://www.agedcareaustralia.gov.au/internet/AgedCare/Publishing.nsf/Content/NRCP-1>.
- Government of Canada. "Social Union Framework Agreement Review." N.d. Retrieved May 1, 2008, at: http://www.unionsociale.gc.ca/menu_e.html.
- Government of Canada. "A framework to improve the social union for Canadians: An agreement between the Government of Canada and the governments of the provinces and territories." News release, February 4, 1999. Retrieved May 1, 2008, at: http://www.unionsociale.gc.ca/news/020499_e.html.

- Government of New Brunswick. *Healthcare Without Walls: The New Brunswick Extra-Mural Program*. <http://www.gnb.ca/0051/0384/pdf/1985e.pdf>.
- Government of Northwest Territories. *Integrated Service Delivery Model of the Northwest Territories*. http://www.hlthss.gov.nt.ca/pdf/reports/health_care_system/2004/english/isdm/isdm_a_detailed_description.pdf.
- Government of Prince Edward Island. "Province announces details of new palliative home care drug program." News release, May 13, 2008. Retrieved Jan. 26, 2009, at: <http://www.gov.pe.ca/news/getrelease.php3?number=5721>.
- Gray, Jonathan. "Home Care in Ontario: The Case for Copayments." *Health Law Journal* 8 (2000): 177–197.
- Health Canada. "An Assessment of Continuing Care Requirements in First Nations and Inuit Communities: Review of Literature and National Health Data Sources." N.d. Retrieved January 14, 2009, at: http://www.hc-sc.gc.ca/fniat-spniat/pubs/services/_home-domicile/2008_assess-lit-exam-doc/05-cost-cout-eng.php.
- Health Canada. "Continuing Care in First Nations and Inuit Communities: Evidence from the Research." N.d. Retrieved March 31, 2008, at: http://www.hc-sc.gc.ca/fnih-spni/pubs/home-domicile/2007_info_contin_care-soins/index_e.html.
- Health Canada. "Health Transition Fund." N.d. Retrieved May 1, 2008 at: http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/finance/hhf-fass/index_e.html.
- Health Canada. *Human Resource Issues in Home Care in Canada: A Policy Perspective*. (Ottawa: Minister of Public Works and Government Services Canada, 1999).
- Health Canada. *Provincial and Territorial Home Care Programs: A Synthesis for Canada*. (Ottawa: Minister of Public Works and Government Services Canada, 1999).
- Health Canada. *Summary of Initiatives, Final Edition*. Part of the Synthesis Series of the Primary Health Care Transition Fund. (Ottawa: Health Canada, 2007).
- Health Canada, Primary Health Care Transition Fund, Initiative Fact Sheet: Prince Edward Island. Accessed March 30, 2009, at: [http://www.apps.hc-sc.gc.ca/hcs-sss/phctf-fassp.nsf/lkAttachments/3AC12830CC235BD48525728E006ACED1/\\$File/31E_FS_PEI.pdf](http://www.apps.hc-sc.gc.ca/hcs-sss/phctf-fassp.nsf/lkAttachments/3AC12830CC235BD48525728E006ACED1/$File/31E_FS_PEI.pdf).
- Health Canada, *Primary Health Care Transition Fund, Summary of Initiatives, Final Edition*, March 2007.
- Health Canada, Home Care and Pharmaceutical Division. *Human Resource Issues in Home Care in Canada: A Policy Perspective*. N.d. Retrieved Jan. 14, 2008, at: www.hc-sc.gc.ca/homecare/english/hr1.html.
- Health Council of Canada. *Health Care Renewal in Canada: Accelerating Change*. (Toronto: Health Council, 2005). www.healthcouncilcanada.ca.
- Health Council of Canada. *The Health Status of Canada's First Nations, Métis and Inuit Peoples*. (Toronto: Health Council, 2005). www.healthcouncilcanada.ca.
- Health Council of Canada. *Why Health Care Renewal Matters. Learning from Canadians with Chronic Health Conditions*. (Toronto: Health Council, 2007). www.healthcouncilcanada.ca.
- Health Council of Canada. *Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada*. (Toronto: Health Council, 2008). www.healthcouncilcanada.ca.
- Health Council of Canada. *Rekindling Reform: Health Care Renewal in Canada, 2003–2008*. (Toronto: Health Council, 2008). www.healthcouncilcanada.ca.
- Health Professions Regulatory Advisory Council. September 2006 letter to to the Ontario Ministry of Health and Long-Term Care in respect of personal support workers. Public release, June 27, 2006.
- Hébert, Réjean. "The Impact of Aging on the Healthcare System: Catastrophe or Catalyst?" University of Sherbrooke, Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA). <http://www.health.gov.bc.ca/hcc/presentation/hebert.pdf>.
- Hébert, Réjean. "Program of Research to Integrate the Services for the Maintenance of Autonomy" (PRISMA). N.d. <http://www.cihr-irsc.gc.ca/e/29971.html>.
- Hébert, Réjean, Pierre Durand and André Tourigny. "Frail Elderly Patients: New Model for Integrated Service Delivery." *Canadian Family Physician* 49 (August 2003): 992–997.
- Hirschfeld, Miriam. "The 'Canadian Model' in the International Context." *HealthcarePapers* 1,4 (Fall 2000): 103–109.
- Hollander Analytical Services. "New study finds home care more cost-effective to government than residential care." News release, November 29, 1999. www.homecarestudy.com/news/ss1pre.html.
- Hollander Analytical Services. *Analysis of Interfaces Along the Continuum of Care Final Report: "The Third Way": A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and Their Families*. Prepared for Home Care and Pharmaceuticals Division, Health Policy and Communications Branch, Health Canada. February 2002. <http://www.hollanderanalytical.com/downloads/continuum-final.pdf>
- Hollander Analytical Services. *Home Care Program Review*. Prepared for Saskatchewan Health, Community Care Branch. February 2006. <http://www.health.gov.sk.ca/adx/adx/adxGetMedia.aspx?DocID=530,94,88,Documents&MediaID=354&Filename=home-care-review-2006-exec-summary.pdf>
- Hollander, Marcus J. *The National Evaluation of the Cost-Effectiveness of Home Care, Substudy 1: The Comparative Cost Analysis of Home Care and Residential Care Services. Preliminary Findings*. November 1999. www.homecarestudy.com.
- Hollander, Marcus J. *The Identification and Analysis of Incentives and Disincentives and Cost-effectiveness of Various Funding Approaches for Continuing Care*. (Victoria: Hollander Analytical Services, May 2000).

- Hollander, Marcus J. *Unfinished Business: The Case for Chronic Home Care Services, A Policy Paper*. (Victoria: Hollander Analytical Services, August 2003 [updated 2004]).
- Hollander, Marcus J. *Continuing Care Service Delivery Systems: Case Studies of Current Models*. January 2007.
- Hollander, Marcus J. "Providing Care and Support for an Aging Population: Briefing Notes on Key Policy Issues." *Healthcare Quarterly* 10,3 (June 2007): 34–45.
- Hollander, Marcus J. "Persons with Ongoing Care Needs and Their Families." *Healthcare Quarterly* 11,1 (January 2008): 45–54.
- Hollander, Marcus J. and E.R. Walker. *Report of Continuing Care Organization and Terminology*. Ottawa: Division of Aging and Seniors, Health Canada, 1998. In Canadian Nurses Association, *A National Approach to Home and Community Care: Through the Lens of the Canada Health Act*. March 2000.
- Hollander Marcus J. and Neena Chappell. *Final Report of the National Evaluation of the Cost-Effectiveness of Home Care*. A Synthesis Report prepared for the Health Transition Fund, Health Canada. August 2002.
- Hollander, Marcus J. and Angela Tessaro. *Evaluation of the Maintenance and Preventive Function of Home Care, Final Report* (Victoria: Hollander Analytical Services, March 2001).
- Hollander Marcus J. and M.J. Prince. *A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and Their Families*. February 2002.
- Hollander, Marcus J., J. Miller, M. MacAdam, N. Chappell and D. Pedlar. "Increasing Value-for-Money in the Canadian Health Care System: New Findings and the Case for Integrated Care for Seniors." Draft of an unpublished paper. November 2008.
- Human Resources and Social Development Canada. "A new Employment Insurance benefit —Compassionate Care Benefit." News release, January 6, 2004.
- IBM Institute for Business Value. "Health 2015: Win-win or Lose-lose?" 2006.
- Indian and Northern Affairs Canada. "INAC's Adult Care Program." Retrieved May 8, 2008, at: http://www.ainc-inac.gc.ca/pr/pub/ae/ev/2003/01-25/01-25_4_e.html.
- Jacobs, Philip (Hollander Analytical Services). *Substudy 9: Costs of Acute Care Services Compared to Home Care Services. Executive Summary*. Retrieved February 2, 2008, at: www.homecarestudy.com/reports/summaries/ss09-es.html.
- Kushner, Carol, Patricia Baranek and Marion Dewar. *Home Care: Change We Need*. Report on the Ontario Health Coalition's Home Care Hearings. November 17, 2008.
- Lafontaine, Carole (National Aboriginal Health Organization). Presentation to the Senate Standing Committee on Aging, November 27, 2006. Retrieved March 31, 2008, at: <http://www.naho.ca/publications/agingPresentation.pdf>.
- Lang, Ariella, Nancy Edwards, Carolyn Hoffman, Judith Shamian, Kathleen Benjamin and Marguerite Rowe. "Broadening the Patient Safety Agenda to Include Home Care Services." *Healthcare Quarterly* 9, Special Issue (October 2006): 124–140.
- Le Goff, Philippe. *Home Care in Manitoba, Saskatchewan, Alberta and British Columbia: Structure and Expenditures*. (Library of Parliament, October 9, 2002). <http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0232-e.htm>.
- Le Goff, Philippe. *Home Care in the Atlantic Provinces: Structures and Expenditures*. (Library of Parliament, October 2, 2002). <http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0230-e.htm>.
- Le Goff, Philippe. *Home Care Sector in Canada: Economic Problems*. (Library of Parliament, October 10, 2002). <http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0229-e.htm>.
- Le Goff, Philippe. *Home Care, and Caring for Persons Suffering from a Long-term Loss of Independence: A Funding Model for Canada*. (Library of Parliament, January 6, 2003). dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/PRB-e/PRB0250-e.pdf.
- Lewis, Ivan. Parliamentary Under Secretary of State for Care Services (England). "Now the elderly will get equal rights." *The Observer*. June 24, 2007. Retrieved April 7, 2008, at: <http://www.guardian.co.uk/commentisfree/2007/jun/24/comment.longtermcare>.
- Liberal Task Force on Seniors. *Liberal Task Force Report*. February 2004.
- Living Lessons®. "Increasing Awareness of Hospice Palliative Care in Canada." Fact sheet. www.living-lessons.org/main/hospice.asp.
- Lum, Janet. "Integrated Care." Presentation at the Canadian Research Network for Care in the Community conference Look Globally, Act Locally: Integrating Care in the Community for Vulnerable Populations. Toronto, October 20, 2008.
- MacAdam, Margaret. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks Research Report. April 2008.
- Makarenko, Jay. *Romanow Commission on the Future of Health Care: Findings and Recommendations*. April 2007. Retrieved May 1, 2008, at: <http://www.mapleleafweb.com/features/romanow-commission-future-health-care-findings-and-recommendations#recommendations>.
- Markle-Reid, Maureen, G. Browne, R. Weir, A. Gafini, J. Roberts and S. Henderson. "Seniors at Risk: The Association Between the Six-Month Use of Publicly Funded Home Support Services and Quality of Life and Use of Health Services for Older People." *Canadian Journal on Aging* 27,2 (2008): 207–224.
- Martin-Matthews, Anne. *Seniors' Health*. Sharing the Learning: The Health Transition Fund Synthesis Series. (Ottawa: Health Canada, 2002).
- Maxwell, Judith. "Out of the ER: Finding the 'right' setting for elderly patients." *The Globe and Mail*, March 24, 2008, p. B2.
- McGill University Health Centre. "Rotman Award recognizes MCH efforts to care for children with complex illnesses in their homes rather than in hospital." News release, June 12, 2006. Retrieved April 1, 2008, at: <http://www.muhc.ca/media/news/?ItemID=20533>.

- Medical News Today, April 2, 2008.
- Miller, Jo Ann and Marcus Hollander. *Synthesis Report — An Assessment of Continuing Care Requirements in First Nations and Inuit Communities*. (Victoria: Hollander Analytical Services Ltd., October 2006).
- Miller, Jo Ann, Marcus Hollander and Margaret MacAdam. "The Continuing Care Research Project for Veterans Affairs Canada and the Government of Ontario." Draft Synthesis Report. January 21, 2008.
- Morris, Marika et al. "The Changing Nature of Home Care and Its Impact on Women's Vulnerability to Poverty." November 1999.
- Motiwala, Sanobar S., Colleen M. Flood, Peter C. Coyte and Audrey Laporte. "The First Ministers' Accord on Health Renewal and the Future of Home Care in Canada. *Longwoods Review* 2,4 (2005).
<http://www.longwoods.com/product.php?productid=17232&cat=370>.
- Multiple Sclerosis Society of Canada. "The Cost of Caring: Implications for Family Caregivers." 2008.
- National Advisory Committee on Aging. *The NACA Position on Home Care*. Position no. 20. (Ottawa: Minister of Public Works and Government Services Canada, 2000).
- National Advisory Council on Aging. "The Seniors of Canada's Far North." *Expression*, 17,2 (Spring 2004).
- National Advisory Council on Aging. *Seniors in Canada: 2006 Report Card*. (Ottawa, 2006).
- National Coordinating Group on Health Care Reform and Women. "Women and Home Care." 2002.
- Neudorf, C. and Franko, J. *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*. www.homecarestudy.com.
- Nies, Henk. "International Perspectives." Presentation at the Canadian Research Network for Care in the Community conference Look Globally, Act Locally: Integrating Care in the Community for Vulnerable Populations, Toronto, Ontario, October 20, 2008.
- No author. *Report to the Annual Premiers' Conference, August 2002*.
- Nosé, Marlene. "The First Nations and Inuit Home and Community Program: Caring for Children: Status, Opportunities and Challenges." Presentation at the symposium Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada, February 20, 2007.
- O'Brien, Linda, Andrea Baumann, Stephen Birch and Gail Tomblin Murphy. "Health Human Resource Planning in Home Care: How to Approach It—That Is the Question." *HealthcarePapers* 1,4 (Fall 2000): 53–59.
- O'Brodovitch, Hugh. "Home Health Care: The Next Challenge for Children's Health." *AboutKidsHealth*, October 26, 2005. Retrieved March 5, 2008, at: <http://www.aboutkidshealth.ca/News/Home-health-care-the-next-challenge-for-childrens-health.aspx?articleID=8103&categoryID=news-poh1>.
- The Ontario Home Health Care Providers Association and the Ontario Community Support Association. "Building a High Performance Home and Community Care System in Ontario." Joint position paper, October 31, 2001.
- Ontario Human Rights Commission. "Time for Action: Advancing Human Rights for Older Ontarians." Retrieved April 29, 2008, at: http://www.ohrc.on.ca/en/resources/discussion_consultation/TimeForActionsENGL?page=TimeForActionsENGL-Elder-2.html.
- Ontario Ministry of Health and Long-Term Care. *Realizing the Potential of Home Care: Competing for Excellence by Rewarding Results*. (Toronto: Queen's Printer for Ontario, 2002). (Also known as the Caplan Report.)
- Ontario Ministry of Health and Long-Term Care. "McGuinty government improves home care." News release, May 1, 2006.
- Ontario Ministry of Health and Long-Term Care. *Choosing Quality, Rewarding Excellence*. May 2006.
- Ontario Ministry of Health and Long-Term Care. *Aging at Home Strategy*. August 28, 2007.
- Ontario Ministry of Health and Long-Term Care. "Ontario strengthens home care services: McGuinty government sets standards for high quality of care." News release, December 15, 2008. Retrieved January 20, 2009, at: <http://www.ccac-ont.ca/Upload/ce/General/StrengthensHC.pdf>.
- Ontario Nurses' Association. "ONA Home Care Nurses Deserve Decent Wages, Benefits: Urged Not to Work for New Providers Without Job Security." December 14, 2007.
- Orchard, Margo, Esther Green, Terence Sullivan, Anna Greenberg and Verna Mai. "Chronic Disease Prevention and Management: Implications for Health Human Resources in 2020." *Healthcare Quarterly* 11,1 (2008): 38–43.
- O'Regan, Eilish. "Irish Survey Shows 161,000 Carers Under Threat." *Family Caregiver* (October 2008): 10.
- O'Rourke, Norm, Philippe Cappeliez and Eva Neufeld. "Recurrent Depressive Symptomatology and Physical Health: A 10-Year Study of Informal Caregivers of Persons with Dementia." *The Canadian Journal of Psychiatry* 52,7 (July 2007): 434–439.
- Ostry, Aleck. *Change and Continuity in Canada's Health Care System*. (Ottawa: Canadian Healthcare Association Press, 2006).
- Pan-Canadian Planning Committee on Unregulated Health Workers. "Valuing Health-Care Team Members: Working with Unregulated Health Workers. A Discussion Paper." (Ottawa: Canadian Nurses Association, 2008).
- Parent, Karen and Malcolm Anderson. "Developing a Home Care System by Design." *HealthcarePapers* 1,4 (Fall 2000) 46–53.
- Parent, Karen and Malcolm Anderson. *Home Care by Default, Not by Design*. CARP's Report Card on Home Care in Canada, 2001. (Toronto: CARP Canada's Association for the Fifty-Plus, 2001).
- Parent, Karen, Malcolm Anderson and Barbara Neuwelt. *Home Care and People with Psychiatric Disabilities: Needs and Issues. A National Evaluation*. (Toronto: Canadian Mental Health Association, 2000).
- Parliament of Australia. "Caring for the Elderly: An Overview of Aged Care Support and Services in Australia." E-brief from the Parliamentary Library, February 27, 2003 (updated April 30, 2003). <http://www.aph.gov.au/library/intguide/SP/agedcare.htm>.

- Patel, Hema and Isabelle St. Sauveur. "The Intensive Ambulatory Care Service: A Medical Home for Children with Complex Medical Needs." Presentation at the symposium Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada, February 20, 2007.
<http://www.crncc.ca/events/download/HemaPatelandIsabelleStSauveur-February20thpresentation.pdf>.
- Pollara. *Health Care in Canada. 10th Anniversary Survey Results, Part 1*. December 2007.
- Protti, Dennis J. *Information Management and Technology*. Part of the Synthesis Series of the Primary Health Care Transition Fund. (Ottawa: Health Canada, 2007).
- Quality End-of-Life Care Coalition of Canada. *A Pan-Canadian Partnership for Palliative and End-of-Life Care*. August 2007.
http://www.chpca.net/qelccc/information_and_resources/QELCCC_Pan_Cdn_Partnership_2007.pdf.
- Quality End-of-Life Care Coalition of Canada. *Hospice Palliative Home Care in Canada: A Progress Report*. (Ottawa: Quality End-of-Life Care Coalition of Canada, May 2008).
- Quality End-of-Life Care Coalition of Canada. "New QELCCC Report: Provinces and Territories Making Progress in Providing Palliative Home Care but Inequalities in Access Still Exist." *AVISO 56* (Summer 2008).
- Revill, Jo. "Revolution in Home Care for Old People," *The Observer*, December 9, 2007.
www.guardian.co.uk/society/2007/dec/09/longtermcare.
- Richardson, Blair. "Implementing Home Care in Canada: Four Critical Elements." *HealthcarePapers* 1,4 (Fall 2000): 67–74.
- Romanow, Roy J. *Building on Values: The Future of Health Care in Canada*. Final Report of the Commission on the Future of Health Care in Canada. (Ottawa: Queen's Printer, November 2002.)
- Sargious, Peter. *Chronic Disease Prevention and Management*. Part of Sharing Insights: Primary Health Care Transition Fund Synthesis Series. (Ottawa: Health Canada, 2007).
- Saskatchewan Seniors Mechanism. Presentation to the Prime Minister's Task Force on Seniors. November 28, 2003.
- Sears, Nancy. "Redesigning Community Health: Where the Individual Needs of Seniors Drive the Supply of Services." Presentation at Re-Imagining Health Services: Innovations in Community Health, November 6–8, 2008, Vancouver, British Columbia.
- Seow, Helen, Susan King and Vida Vaitonis. "The Impact of Ontario's End-of-Life Care Strategy on End-of-Life Care in the Community." *Healthcare Quarterly* 11,1 (2008): 57–61.
- Shamian, Judith. "Care Outside of Hospitals. Regionalization: Integration That Did? Or Did Not? Happen: A Frontline Perspective." Presentation at the National Healthcare Leadership Conference, Saskatoon, Saskatchewan, June 2, 2008.
- Shamian, Judith, Esther Shainblum and Jennifer Stevens. "Accountability Agenda Must Include Home and Community-Based Care." *HealthcarePapers* 11,1 (2007).
- Shapiro, Evelyn. "The Romanow Commission Report and Home Care." *Canadian Journal on Aging* 22,1, (2003): 13–17.
- Shapiro, Evelyn. "Reaching a Federal/Provincial Consensus on Home Care." *HealthcarePapers* 1,4 (Fall 2000): 85–91.
- Shapiro, Evelyn. *Home Care*. Sharing the Learning: The Health Transition Fund Synthesis Series. Catalogue No. Cat. H13-6/2002-2. (Ottawa: Health Canada, 2002).
- Sharkey, Shirlee. "A Living Framework: Evolving from Traditional Care to Individual Mastery." *HealthcarePapers* 1,4 (Fall 2000): 80–85.
- Sholzberg-Gray, Sharon. "The Patchwork Quilt of Care Outside of Hospitals: Regional or Pan-Canadian Solutions?" Presentation at the National Healthcare Leadership Conference, Saskatoon, Saskatchewan, June 2, 2008.
- SickKids Foundation. "Children's Network of Simcoe York awarded \$100,000 prize for creating integrated homecare model." News release, June 16, 2008. Retrieved January 9, 2009, at:
<http://www.ctn-simcoeyork.ca/resources/Rotman%20Award%20Release%202008%20Final%20for%20web%20posting.pdf>.
- Sinclair, Duncan. "Speaking with Michael Kirby." *Healthcare Quarterly* 5,4 (2002): 32–39.
- South East Local Health Integration Network. "'Aging at Home' kick-off in the South East: Area seniors meet with Local Health Integration Network; Forum is start of consultations for \$17.4M initiative to support seniors in their homes." Media release, October 15, 2007.
- Standing Senate Committee on Social Affairs, Science and Technology. *Quality End-of-Life Care: The Right of Every Canadian, Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, Final Report*. June 2000.
<http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>.
- Standing Senate Committee on Social Affairs, Science and Technology. *The Health of Canadians — The Federal Role. Volume Five: Principles and Recommendations for Reform — Part I*. (Ottawa, April 2002).
- Standing Senate Committee on Social Affairs, Science and Technology. *The Health of Canadians — The Federal Role, Final Report. Volume Six: Recommendations for Reform*. (Ottawa, October 2002).
- Statistics Canada. "A Profile of Disability in Canada, 2001. A Profile of Disability Among Children. Participation and Activity Limitation Survey 2001." N.d. Retrieved December 3, 2008, at: <http://www.statcan.gc.ca/pub/89-577-x/4065023-eng.htm>.
- Statistics Canada. "2006 Census: Age and Sex." *The Daily*, July 17, 2007. Retrieved July 18, 2008, at
<http://www.statcan.ca/Daily/English/070717/td070717.htm>.
- Statistics Canada. "Participation and Activity Limitation Survey." *The Daily*, December 3, 2007, p. 3. Retrieved October 16, 2008, at:
www.statcan.gc.ca/daily-quotidien/071203/dq071203a-eng.htm.
- Statistics Canada. "Deaths." *The Daily*, January 14, 2008.

- Stewart, Miriam J. and Lynn Langille. "A Framework for Social Support Assessment and Intervention in the Context of Chronic Conditions and Caregiving," *Chronic Conditions and Caregiving in Canada: Social Support Strategies*. (Toronto: University of Toronto Press, 2000).
- Strengthening Home and Community Care Across Canada: A Collaborative Strategy*. Report to the Annual Premiers' Conference. August 2002. http://www.hltss.gov.nt.ca/pdf/reports/home_and_continuing_care/2002/english/strengthening_home_and_community_care_across_canada.pdf.
- Swane, Christine. "As Good as It Gets — in Denmark: From Preventive Home Visits to Reminiscence and Nature in Dementia Care." Presentation at the Re-Imagining Health Services: Innovations in Community Health Conference, Vancouver, British Columbia, November 7, 2008.
- Tam, Pauline. "The Eldercare Gap." Part 5 of The Age of Methuselah: Canada's Longevity Boom series on aging in *The Citizen*, February 2–6, 2008. February 6, 2008, p. C3.
- Taylor, Richard W. "The Future of Home Healthcare in Canada." *CARP Action*. February 2006.
- Thompson, Laurence G. "Clear Goals, Solid Evidence, Integrated Systems, Realistic Roles." *HealthcarePapers* 1,4 (Fall 2000): 60–67.
- Torjman, Sherri. "What Are Policy-Makers Saying About Respite?" (Caledon Institute of Social Policy, February 2003).
- U.K Community Care. "It Pays to Be Direct." November 11, 2004. Retrieved August 20, 2008, at: <http://www.communitycare.co.uk/Articles/2004/11/11/47062/it-pays-to-be-direct.html>.
- University of Alberta. Untitled website. Statistical information on various health initiatives and telehealth. N.d. <http://www.albertatelehealth.com/library/Home%20Telehealth%20Table.doc>.
- University of Alberta. "Reworking Work: The Experiences of Employed Caregivers of Older Adults." Hidden Costs, Invisible Contributions project. Fact sheet. June 2005. Accessed March 26, 2009 <http://www.uofaweb.ualberta.ca/rapp/pdf/ReworkingworkMay31FINAL.pdf>.
- University of Alberta. "Monetizing the Costs to Caregivers." Hidden Costs, Invisible Contributions project. PowerPoint slides. February 22–23, 2007.
- University of Alberta. "Family/Friend Caregiving in Canada: Gender Matters." Research on Aging Policies and Practices. Fact sheet. October 2007. <http://www.ales2.ualberta.ca/hecol/rapp/publications/gender%20fact%20sheet.pdf>.
- Vass, Mikkel, Kirsten Avlund, Carsten Hendriksen, Rasmus Holmberg, Henrik Fiil Nielsen and AgeForum. *Older People and Preventive Home Visits*. (Denmark: AgeForum, September 2006). Retrieved January 14, 2009, at: <http://www.aeldreform.dk/wm141970>.
- Victorian Order of Nurses. *VON Caregiving Program: An Overview*. December 2005. <http://www.von.ca/doc/VON%20Canada%20Caregiving%20Program.doc>
- Victorian Order of Nurses. "South East LHIN 'smiles' on VON: VON selected as regional management centre for innovative seniors program." News release, February 28, 2008.
- Victorian Order of Nurses. "In the caring hands of your neighbour: VON expands neighbours helping neighbours program." News release, June 10, 2008.
- Vogel, Donna. "Lies Told to the Sick and Weak." *HealthcarePapers* 1,4 (Fall 2000): 96–98.
- Waisberg, Frieda. "Health Human Resources — Registered Nurses and Licensed Practical Nurses." Notes from the Care in the Community and Health Human Resources symposium, Ryerson University, Toronto, March 18, 2008. <http://teamgrant.ca/2008sym.php>,
- Waisberg, Frieda Audrey Laporte, Carey Levinton, Raisa Deber, Linda O'Brien-Pallas, Andrea Baumann and Kanecy Onate. "The Importance of Nurse Employment Categories in Determining Exit Rates from Nursing." <http://teamgrant.ca/Posterandpress/2008sym/6.2%20Frieda.pdf>. Presentation by the CIHR Team in Community Care and Health Human Resources, at the Care in the Community and Health Human Resources symposium, Ryerson University, Toronto, March 18, 2008. <http://teamgrant.ca/2008sym.php>.
- Wanless, Derek. *Securing Good Care for Older People*. (London: King's Fund, March 2006). Accessed March 26, 2009 http://www.kingsfund.org.uk/publications/the_kings_fund_publications/securing_good.html
- White, Sheri and Janice Keefe. *Paying Caregivers: A Briefing Paper*. 2005.
- Wiles, Janine L. and Mark W. Rosenberg. "Paradoxes and Contradictions in Canada's Home Care Provision: Informal Privatization and Private Informalization." *International Journal of Canadian Studies* 28 (2003): 63–89.
- Wilkins, Kathryn. "Government-subsidized Home Care." *Health Reports* 17,4 (October 2006): 39–42. Statistics Canada Catalogue No. 82-003.
- Williams, A. Paul. "Evidence in Action: Mobilizing Knowledge in Home and Community Care." Presentation to the St. Elizabeth Health Care Centre Conference, March 2008. http://www.ryerson.ca/crncc/knowledge/events/download/EvidenceinAction-St.Elizabethpresentation_pw08.pdf.
- Williams, A. Paul. "Forging Ahead, Evidence to Innovation." Presentation, March 8, 2008. www.crncc.ca.
- Witmer, Elizabeth. "Bring Health Care Closer to Home: One Province's Approach to Home Care." *HealthcarePapers* 1,4 (Fall 2000): 98–103.
- Woodward, Christel A. "Home Care in Australia, Some Lessons for Canada." McMaster University Centre for Health Economics and Policy Analysis (CHEPA) Working Paper 04-02, July 2004.
- ZDNet News. "Short of Staff, Norway Eyes Robot Care for Elderly." February 7, 2008. http://news.zdnet.com/2100-9595_22-6229581.html?tag=nl.e539.

Zeytinoglu, Isik U. and Margaret Denton. *Satisfied Workers, Retained Workers: Effects of Work and Work Environment on Homecare Workers' Job Satisfaction, Stress, Physical Health, and Retention. Key Implications for Decision Makers*. Canadian Health Services Research Foundation, December 2005. Retrieved November 28, 2008, at: http://www.chsrf.ca/final_research/ogc/zeytinoglu_e.php.

Some Major Websites

Canadian Caregiver Coalition. <http://www.ccc-ccan.ca/index.php>

Canadian Home Care Association. www.cdnhomecare.ca

Health Canada, Health Transition Fund.

<http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/finance/hf-fass/proj/proj-jur-eng.php>

Health Canada, Primary Health Care Transition Fund. <http://www.hc-sc.gc.ca/hcs-sss/prim/phctf-fassp/index-eng.php>

Carers Australia. <http://www.carersaustralia.com.au/>

Carers New Zealand. <http://www.carers.net.nz/>

Carers UK. <http://www.carersuk.org>

Appendix One

Visions and Targets for Home Care

	British Columbia	Saskatchewan	Manitoba	Ontario
VISION	<p>To provide individuals with the support and health services they need to live fully and independently or interdependently as valued members of their community. B.C.'s home and community care services system will respect, recognize and support clients, their caregivers and their service providers.</p>	<p>Home care is an integral part of a continuum and includes community as well as institutional services; both are seen as necessary to ensure the best possible quality of life for people with varying degrees of short- and long-term illnesses.</p>	<p>To ensure provision of effective, reliable and responsive home health care services to Manitobans so as to support independent living in the community.</p> <p>To ensure coordination of admission to facility care when living in the community is not a viable alternative. Regional health authorities (RHAs) are developing community living alternatives, which delay the need for facility care.</p>	<p>To help people stay healthy, support their personal responsibility, and provide effective, accessible, quality care where and when needed, through health care policies and standards developed by the Health Program Policy and Standards Branch, as part of the Health System Strategy Division. Such policies and standards are seen as part of a sustainable, publicly funded system.</p>

Visions and Targets for Home Care

British Columbia	Saskatchewan	Manitoba	Ontario	TARGETS
<p>Target to be determined for home care rate.</p> <p>Performance targets relating to deaths out of hospital for end-of life (EOL) measures:</p> <ul style="list-style-type: none"> • Provincial long-term target is 60%. • Provincial benchmark is 50%. 	<p>Saskatchewan's current level of home care services continues to exceed the First Ministers' commitment in the 10-year plan of 2004. Saskatchewan continues to be committed to maintaining a high level of home care services.</p>	<p>Each RHA is targeting development that is based on identified needs.</p>	<p>Establish clear directives for providing access to services in targeted sectors (program designs, standards, policies, regulations, legislation).</p> <p>Increase effectiveness of policies for accessing health care services by sector.</p> <p>Improve the quality of designs, policies and standards for health care programs.</p> <p>Increase integration and alignment between program policy change initiatives.</p>	

Visions and Targets for Home Care

	British Columbia	Saskatchewan	Manitoba	Ontario
MEASURES	<p>Health System Performance Improvement Measure for 2007/2008:</p> <p>Age-standardized client count rate per 1,000 population for assisted living programs, adult day programs, home support / Choice in Supports for Independent Living, and direct care service types, clients aged 65 and over.</p> <p>In the health authorities' 2005/06–2007/08 Performance Agreement, the Ministry of Health included two new performance measures for EOL care, focused on the percentage of natural deaths occurring in settings outside hospitals within each health authority:</p> <ul style="list-style-type: none"> • Percentage of deaths from cancer increased from 45.3% in 2005 to 49.7% in 2006. • Percentage of non-cancer deaths increased from 45.9% in 2005 to 47.3% in 2006. 	<p>RHAs are asked to report on the delivery, development and enhancement of services as part of accountability requirements for Saskatchewan Health.</p>	<p>Performance indicators are established for each of the goals/objectives of the Manitoba home care program.</p>	<p>Develop program performance measures and monitor and evaluate mechanisms for application across the province.</p>

Visions and Targets for Home Care

New Brunswick	Prince Edward Island	Nova Scotia	Newfoundland and Labrador	Yukon	
<p>To integrate all services and bring them closer to people in their homes, including enhancing the <i>Extra-Mural Program</i>. Telehealth and e-health to figure prominently in this goal. New Brunswick is also currently developing a new provincial health plan.</p>	<p>To continue providing a wide range of services in home care, with focus on greater attention to exploring service delivery models. Additional resources would be required to make the vision fully operational.</p>	<p>To provide safe, quality care in the home, allowing people to stay in their own home for as long as is beneficial to their health.</p>	<p>To achieve a consistent approach to home care delivery throughout the province, supporting individuals and families and empowering them to achieve their optimal functioning, health and well-being in the setting of their choice.</p>	<p>To support people's diverse needs for quality of life and living independently. Yukon Home Care supplements other community supports and is linked to a continuity of health care services.</p>	<p>VISION</p>

Visions and Targets for Home Care

	New Brunswick	Prince Edward Island	Nova Scotia	Newfoundland and Labrador	Yukon
TARGETS	<p>Family and Community Services is currently developing a 10-year strategy for long-term care services. Strong commitment with New Brunswick's Extra-Mural Program to remain innovative in meeting the needs for home health care now and in the future.</p> <p>Continue to improve the remote monitoring program to integrate with the clinical information system.</p>	<p>Following a restructuring of the Department of Health, a strategic plan has been developed but has not yet been approved.</p>	<p>Enhance palliative care services.</p> <p>Increase budget allotment for home adaptation and repair programs.</p> <p>Where possible, shift mental health services to be home-based rather than hospital-based.</p>	<p>Identify core services of home care and minimize discrepancies between service delivery areas.</p>	<p>Enhance data collection at the point of care.</p> <p>Develop and implement electronic health records (EHRs) to support delivery of home care service.</p> <p>Apply interRAI tools to assist with focused individual care planning processes.</p> <p>Enhance supports for delivery of services in rural and remote locations.</p>

Visions and Targets for Home Care

New Brunswick	Prince Edward Island	Nova Scotia	Newfoundland and Labrador	Yukon	
<p>Home care programs are accumulating the required data to satisfy demands for evidence-based decision making.</p>	<p>Work is in progress.</p>	<p>First phase of palliative care entitlements has been completed; services can be accessed from anywhere in the province at first-dollar coverage during the last three months of life.</p>	<p>Quarterly reports began on April 1, 2007. Reports are to contain indicators of service delivery.</p> <p>Continued enhanced usage of the client referral management system (CRMS).</p> <p>Continue working with Canadian Institute for Health Information (CIHI) and interRAI projects to develop the minimum data set.</p>	<p>Yukon is currently the only jurisdiction that feeds live data to CIHI's Home Care Reporting System.</p> <p>EHR is in place and is audited semi-annually.</p> <p>interRAI data are reported quarterly to CIHI.</p> <p>Needs assessment conducted in three Yukon communities annually.</p>	<p>MEASURES</p>

Visions and Targets for Home Care

	Northwest Territories	Nunavut	Canadian Forces	Health Canada
VISION	To meet individual needs in the least intrusive manner, promoting the greatest opportunity for lasting wellness and functional independence.	To maintain and increase capacity to support people in their own communities and homes for as long as possible, resulting in less dependence on facility-based acute care.	To assist clients to remain healthy and independent and in their own homes and communities, through Veterans Affairs Canada's (VAC's) national home care program. The program includes services such as housekeeping, groundskeeping, and personal care. A programs-of-choice component provides benefits such as special equipment and therapeutic services to ensure that equipment and services continue to be appropriate for clients' needs.	To provide basic home and community care services that are comprehensive, culturally sensitive, accessible, effective and equitable and that respond to the unique health and social needs of First Nations and Inuit peoples, through the First Nations and Inuit Home and Community Care Program. The program is a coordinated system of home- and community care—based health-related services that enable people with disabilities, chronic or acute illnesses, and those who are elderly to receive the care they need in their home communities.

Visions and Targets for Home Care

Northwest Territories	Nunavut	Canadian Forces	Health Canada	
<p>Every resident of Northwest Territories to have access to increased quantity and quality of services provided by highly skilled and certified employees.</p>	<p>No further specific targets since meeting Accord commitments.</p> <p>Enhance additional therapies (e.g. occupational therapy, physiotherapy, language therapy) to strengthen the home care program.</p>	<p>Continue regular reviews of its comprehensive home care program, Veterans Independence Program (VIP), and add new benefits or modify existing programs as necessary. Any new therapies or other interventions proposed for inclusion must be supported by independent medical research.</p>	<p>Not provided.</p>	<p>TARGETS</p>

Visions and Targets for Home Care

	Northwest Territories	Nunavut	Canadian Forces	Health Canada
MEASURES	<p>To better measure progress on home care, NWT is looking at enhancing its data-gathering system through such methods as collecting data similar to the interRAI project. Such things as adverse-event reporting and the system of indicator development exhibited by the interRAI project are being considered for adoption into NWT's continuing care strategy.</p>	<p>Diagnostic data are focused primarily on acute and chronic disease management.</p> <p>Hours of service by type of patient are monitored.</p> <p>Overall service utilization is monitored and analyzed regionally, locally and across the territory.</p>	<p>The VAC home care program is evaluated regularly. The last five years have seen a renewed emphasis on quality assurance and improvement.</p> <p>As a fundamental component of the case-management process, clients receiving services under the national VIP are closely monitored and regularly reassessed to ensure that health, functional status, and overall well-being remain at an optimum.</p>	<p>Communities are required to submit monthly program delivery statistics. The data, including non-identifying patient demographic information as well as the type and hours of service provided, are collected electronically.</p> <p>First Nations communities are encouraged to follow the direction of their provincial/territorial counterparts with regard to developing IT strategies. As communities move towards an electronic medical record, they will be encouraged to implement home care assessment tools, as per their P/T counterparts.</p>
<p>Source: Health Council of Canada. Table 3, <i>Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada</i>. (Ottawa: Health Council of Canada, January 2008). Reproduced with permission.</p>				

Appendix Two

Expanding Access to Home Care Services: Selected Activities

	British Columbia	Saskatchewan	Manitoba
OBJECTIVES	<p>To optimize the health of persons with functional impairment due to aging, illness or disability by expanding and redesigning the home and community care system to improve access to, and choice within, an enhanced range of community support options.</p>	<p>Home care is a key component of primary health care (PHC) renewal. As an example, home care professionals are part of PHC teams. The goal is for 100% of Saskatchewan residents to have access to these teams by 2011.</p> <p>Mental health home care and crisis response have been implemented and require monitoring and review.</p>	<p>To ensure assessment of client care needs and eligibility for home care services.</p> <p>To ensure support of clients and their family caregivers so they may remain independent and in the community as long as possible.</p> <p>To ensure provision of services in the home (or an alternative community setting) instead of a care facility, where appropriate.</p> <p>To ensure collaboration with care facilities in effective discharge planning.</p> <p>To ensure coordination of placement in a care facility.</p> <p>To ensure collaboration with communities to develop services to meet changing client needs.</p> <p>To evaluate the impact of the Manitoba Home Care Program on target populations and on other health care delivery systems.</p>

Expanding Access to Home Care Services: Selected Activities

British Columbia	Saskatchewan	Manitoba	SELECTED ACTIVITIES
<p>The Vancouver Island Health Authority (VIHA) has initiated a pharmacy medication assessment and administration project at three pilot sites, [with the intent of expanding] the project across the health authority by spring of 2008. The primary goal is to improve VIHA home and community care clients' safety and health outcomes related to medication use.</p>	<p>In 2006/07, Saskatchewan Health invested and annualized \$2.9 million provincially for the enhancement of acute home care services.</p> <p>This initiative seeks to:</p> <ul style="list-style-type: none"> • increase capacity for short-term acute and end-of-life care; • eliminate personal care fees for short-term acute care for up to 14 days; and • increase case management, home support services, and crisis response for clients with mental illness. 	<p>Manitoba Health's method of program data collation was revised using current technology and human resources.</p> <p>A long-term care strategy, Aging in Place, addresses the need for affordable housing options. The strategy includes building on supports which could reduce inappropriate use of acute care.</p>	

Expanding Access to Home Care Services: Selected Activities

	British Columbia	Saskatchewan	Manitoba
SELECTED ACTIVITIES	<p>A standardized, evidence-based approach (including tools, processes, and guidelines) to medication assessment and administration is to be developed throughout VIHA. The process involves collaboration with community pharmacists who participate in identification of risks and care planning.</p> <p>A late-life depression pilot project has been developed by the home health and mental health programs in Abbotsford and Mission, acting as partners, to evaluate the effectiveness of providing primary care treatment to community-dwelling older adults experiencing depression.</p> <p>The ministry is reviewing the need for possible legislative, regulatory, and policy changes to support end-of-life (EOL) care in areas such as hospice care and advance care planning. In addition, the ministry is supporting research, identifying opportunities to enhance education for professionals, caregivers, and the general public, and working with the BC Medical Association, through the General Practitioners Services Committee, on remuneration issues related to palliative care.</p>	<p>Through community-based service, the initiative also facilitates early hospital discharge, avoids or prevents readmission, and avoids or prevents imminent admission.</p> <p>Saskatchewan Health worked with regional health authorities (RHA) to facilitate the development, implementation and delivery of acute community mental health home care. This includes case management, and professional and home support, without fees, for up to 14 days.</p> <p>In addition, the province contracted Saskatchewan's HealthLine to develop, implement and deliver a provincial mental health and addictions crisis response service. The service was introduced in December 2006.</p>	<p>Manitoba Health's method of program data collation was revised using current technology and human resources.</p> <p>A long-term care strategy, <i>Aging in Place</i>, addresses the need for affordable housing options. The strategy includes building on supports that could reduce inappropriate use of acute care.</p> <p>Provincial networks and other ongoing mechanisms facilitate sharing and collaboration across the province.</p> <p>RHAs are reviewing human resources trends and needs.</p>

Expanding Access to Home Care Services: Selected Activities

British Columbia	Saskatchewan	Manitoba	SELECTED ACTIVITIES
<p>In February 2007, the ministry issued a revised <i>Joint Protocol for Expected/Planned Home Deaths</i>. The protocol outlines procedures for managing anticipated natural home deaths resulting from terminal illness and the roles of the family, various health professionals, and the agencies involved. First developed in 1996, the protocol has been well received and successful in directing families, first responders and health care providers in planning for home deaths and in responding appropriately at the time of death.</p> <p>The BC NurseLine has provided enhanced training to all its nurses on responding to EOL care issues. Under a project initiated with the Fraser Health Authority (FHA) in 2004, BC NurseLine also now makes direct referrals after hours (9:00 p.m. to 8:00 a.m.) to FHA's on-call palliative providers. Based on an evaluation of its success, other health authorities are now looking to implement a similar service. In June 2006, this innovative palliative telenursing service won the Tommy Douglas 2006 Protection of Medicare award.</p>			

Expanding Access to Home Care Services: Selected Activities

	British Columbia	Saskatchewan	Manitoba
CHALLENGES	<p>Too often, hospital care is being used as a substitute for home care rather than the other way around.</p> <p>Ensuring provision of a wide range of services across the province, including in rural and remote areas, remains a challenge.</p> <p>Other challenges include:</p> <ul style="list-style-type: none"> • an aging workforce; • introduction of new technology; • lack of comprehensive, integrated information systems in the community sector; and • integration with other health sectors. 	<p>Recruiting/retaining health professional staff and workers in both urban and rural/remote areas presents challenges in the delivery of home care.</p> <p><i>Working Together: Saskatchewan's Health Workforce Action Plan</i> sets a direction for a more integrated workforce and includes initiatives and innovations to improve health workplaces and to address issues affecting key health professionals.</p>	<p>Sustaining human resources, including staff recruitment, training and retention.</p> <p>Increasing complexity of clients' care needs.</p> <p>Expanding use of in-home medical technology and resulting HR and training requirements.</p> <p>Access of all RHAs to electronic assessment tools to further facilitate quality decision making.</p> <p>Improving community attitudes towards care providers and towards living in alternative community environments.</p>

Expanding Access to Home Care Services: Selected Activities

Ontario	New Brunswick	Prince Edward Island	Nova Scotia	OBJECTIVES
<p>To support individuals to remain and age in their home and community, and to relieve pressures on hospitals, the Health Program, Policy and Standards Branch (HPPSB) continues to demonstrate and pursue the benefits of community care over higher-cost institutional care.</p> <p>By the end of 2007/08, Community Care Access Centres (CCACs) are expected to achieve their client targets. From 2003/04 through the end of 2007/08, enhancements to home care funding delivered through CCACs will have provided an additional 95,700 Ontarians with short-term acute care in their homes, and EOL care to another 6,000 clients.</p>	<p>Any door should be the right door when it comes to patients' enquiries about their health, and patients should be able to access the same information throughout the health system.</p>	<p>To plan for province-wide delivery of home care services so that consistency of available services is ensured and provided.</p>	<p>To achieve greater development of regional management.</p> <p>As the Department of Health does not provide services directly, it must provide for an array of services that are consistent across the province and that meet policy requirements. It must evaluate practices and ensure that standards and procedures are being followed by contracted agencies.</p>	

Expanding Access to Home Care Services: Selected Activities

	Ontario	New Brunswick	Prince Edward Island	Nova Scotia
SELECTED ACTIVITIES	<p>Funding is being targeted at two key strategies, acute hospital replacement and EOL care, thus supporting the government's commitment to strengthening the home care sector.</p> <p>End-of-Life Care Strategy For people in the last stages of their lives, this strategy shifts care from hospitals to home or another appropriate setting of the client's choice. The strategy also aims to enhance an interdisciplinary team approach to care in the community and is working towards better coordination and integration of local services.</p> <p>Funding to support nursing and personal support services in residential hospices in more than 30 communities by 2007/08 is also included. Residential hospices offer care, compassion and dignity to those who are in their last stages of life, while providing needed support to their families.</p>	<p>The Extra-Mural Program (EMP) has recently been enhanced by the recent Self-Sufficiency Task Force, with a particular focus on bringing services closer to people in their own homes.</p> <p>Self-management and appropriate levels of self-reliance are being promoted in all aspects of home care, including mental health.</p>	<p>The palliative care program is the best example of integrated practice that the provincial home care program has been able to implement and sustain.</p>	<p>The Continuing Care Branch has been working with the Department of Community Services on housing and home adaption programs, and district network committees have been working with the District Health Authorities, with the goal of wrapping services around the clients so that they are not intrusive, and to manage clients in supportive environments.</p>

Expanding Access to Home Care Services: Selected Activities

Ontario	New Brunswick	Prince Edward Island	Nova Scotia	SELECTED ACTIVITIES
<p>Aging at Home Strategy The strategy is intended to help seniors stay healthy and to live more independently in their own homes by providing seniors and their caregivers with an integrated continuum of community-based services. The strategy was announced on August 28, 2007, by the Ministry of Health and Long-Term Care, with \$702 million in new funding over the next three years. Funding is to be directed at traditional services, including:</p> <ul style="list-style-type: none"> • community support services; • home care; • assistive devices; • supportive housing services; • long-term care beds; and • EOL care. <p>As well, the strategy works to link the above services and providers with new and innovative approaches to service and non-traditional providers.</p>				

Expanding Access to Home Care Services: Selected Activities

	Ontario	New Brunswick	Prince Edward Island	Nova Scotia
SELECTED ACTIVITIES	<p>In addition, the government announced funding of \$13.7 million on February 16, 2007, of community-based health care providers. A portion of this is for CCACs.</p> <p>Announced on October 27, 2006, a three-point action plan to relieve pressure on emergency departments (total investment of \$142 million) included:</p> <ul style="list-style-type: none"> • \$30 million — one-time funding in 2006/07 for CCACs to better serve the needs of their clients and to provide services that appropriately meet their needs and allow people to remain safely, comfortably, and independently in their homes for longer. • \$5.3 million — for community services as part of a multi-year strategy to address pressures in 10 communities; some of this funding was to be allocated to CCACs. 			

Expanding Access to Home Care Services: Selected Activities

Ontario	New Brunswick	Prince Edward Island	Nova Scotia	CHALLENGES
<p>To provide increasing support for an aging population.</p> <p>To relieve pressures in hospitals and long-term care homes.</p> <p>To provide the right services, in the right place, and at the right time to ensure seniors are cared for with the best support possible.</p>	<p>New Brunswick’s home care plan reflects the reality that the health care system does not have the capacity to provide home nursing care 24 hours a day, 7 days a week. Acknowledging the idea that empowering patients to self-manage their health is not new, the plan has a strong focus on client service with clients actively involved in their own care decisions. This move away from health professionals dictating health goals to patients and patients taking a more active role in their own care represents a continuing, fundamental change in focus.</p>	<p>Allocation of scarce financial resources.</p> <p>Multiple agendas within the health care system.</p>	<p>Human resources may be a factor in rural and remote areas. Recruitment and retention are both significant issues. The Department of Health works with contracted agencies to develop HR strategies throughout the sector.</p>	

Expanding Access to Home Care Services: Selected Activities

	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut	Canadian Forces	Health Canada
OBJECTIVES	<p>To achieve consistency in assessment and delivery of home care, regardless of the RHA delivering services.</p> <p>To develop new mandates for core services (e.g. nursing care or long-term care components) to better integrate the components.</p> <p>The provincial home care division has identified home care as an integral component of primary health care.</p>	<p>To support clients' diverse needs towards quality of life and living independently.</p> <p>Home care is intended to supplement other community supports and is linked to a continuity of health care services.</p>	<p>A needs assessment of current clients accessing home and community care [was planned to] be completed by March 2008. From there, a plan will be developed to include short- and long-term goals for home and community care that will integrate with the <i>Continuing Care Strategy and Action Plan</i> currently in development.</p> <p>NWT is committed to expanding access to social respite care under the umbrella of continuing care through the home and community care stream. A successful pilot respite program in Yellowknife will be expanded to other communities in the future.</p>	<p>Specific new initiatives include training programs, such as training home and continuing care workers. Efforts are being made to design a curriculum that would work for staff both in a facility environment and in the community. The focus is on capacity building.</p>	<p>To provide a wide range of services and programs to veterans based on eligibility and need. Clients are regularly screened, assessed and monitored in order to identify care and service requirements.</p>	<p>To foster better integration at the community level with community PHC services as well as with the assisted living program funded by Indian and Northern Affairs Canada, home and community care funding has been moved into a cluster with PHC. This approach will support clients' better access to a comprehensive continuum of care.</p>

Expanding Access to Home Care Services: Selected Activities

Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut	Canadian Forces	Health Canada	SELECTED ACTIVITIES
<p>All funding allocated under the Accord for home care nursing went into client services. The funding was directed to the regions based on their own needs assessments.</p> <p>Prior to the new funding, only those clients living in St. John's had access to home intravenous therapy. Now, that service is available across the province, delivered by community health nurses.</p> <p>A four-week EOL home care program means that, should clients choose to die in their own homes, their families would not bear the financial burden for the clients' pain medication or home support. This is viewed as a significant support to the families.</p>	<p>Current developments in home care include implementing EHRs and applying interRAI tools to assist with focused, individual care planning processes.</p> <p>Yukon is currently the only jurisdiction that feeds live data to CIHI's home care reporting system.</p>	<p>The action plan also includes objectives for enhancing continuing care, such as:</p> <ul style="list-style-type: none"> • services for adults and elderly persons, through enhancing home and community care positions; • completing renovations of several long-term care facilities; • support planning for a dementia facility in 2007/08. <p>To enhance supported living options for adults with disabilities or mental illnesses, a plan [was] to be completed in 2008.</p>	<p>Nunavut has been successful in implementing a home care program and in creating and training a home care group workforce.</p> <p>Work continues to progress towards integrating home care with other dimensions of primary health care.</p> <p>Case management and the enhancement of additional therapies — such as occupational therapy, physiotherapy, and language therapy — have been targeted for future development.</p>	<p><i>The Veterans Independence Program (VIP)</i>, a comprehensive national home care program, has been offered to eligible veterans for over 20 years.</p> <p>VIP services may include grounds maintenance, housekeeping, and personal care services such as assistance with bathing, dressing and eating. These services make a tremendous impact on an individual's ability to remain at home.</p>	<p>Not provided.</p>	

Expanding Access to Home Care Services: Selected Activities

	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut	Canadian Forces	Health Canada
CHALLENGES	Recruitment and retention of health professionals, including nurses, occupational therapists and other professionals, is a challenge.	Yukon is experiencing an ongoing and growing need for long-term supports for younger people with medically complex and chronic conditions. Communications and transportation challenges are a significant part of the potentially high cost associated with extending access to home care to all Yukon residents.	Not provided.	Recruiting and retaining home care nurses is a challenge, as is retaining home support workers and recruiting individuals with formal training. Frequently, not enough candidates have formal training, so on-the-job training is provided as an interim step before individuals get formal training.	The capacity of clients to access services may vary with marketplace conditions in the provinces or health regions. Provincial programming may vary in terms of what is offered and the time frames relating to accessing services. VAC works in close collaboration with other jurisdictions so that veterans may receive required services in a timely manner.	Wage disparities, isolation, nursing shortages and lack of professional support are often cited as deterrents for service providers. Lack of educational preparedness is a major barrier to recruitment.

Source: Health Council of Canada. Table 4, *Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada*. (Ottawa: Health Council of Canada, January 2008). Reproduced with permission.

Appendix Three

Co-payments and Income Testing

	British Columbia	Home support is an income-tested program, with the exception of two weeks' post-acute home support or palliative care. The client rate is based on net income minus deductions for living expenses. In the case of serious financial hardship, clients can seek a rate reduction. Home support fees were capped at \$300 per month in 2005.
	Alberta	Home support is income tested, with consideration given to both the size of the family and income. The fee is based on a sliding schedule. People who receive the <i>Alberta Widows' Pension, Guaranteed Income Supplement, Supports for Independence, or Assured Income for the Severely Handicapped</i> are eligible for a fee exemption. Fees may be waived if they cause undue hardship. A client may pay for home support at \$5 per hour to a maximum of approximately \$300 per month, at which point the client no longer has to pay.
	Saskatchewan	Income-tested fees are applied to clients for chargeable services (meals, homemaking and home maintenance) after their first 10 units (an hour or a meal) of service in a month. In 2007, the first 10 units of service were \$6.96 per unit per hour, and after the 10th unit, fees are charged based on the client's ability to pay.
	Manitoba	There are no fees for home care services, but adult day care, meals on wheels and facility respite have direct fees.
	Ontario	There are no co-payments or income testing for home care services for those who have been assessed as needing home care (those with a temporary incapacity, those who are palliative and those with a disability).
	Quebec	There are no co-payments or income testing for home care services for those who have been assessed as needing home care (those with a temporary incapacity, those who are palliative and those with a disability).
	New Brunswick	Long-term supportive and residential care is income tested according to net income. There are no charges for professional services. There is a client contribution based on income testing for home support services through Family and Community Services. As in the rest of Canada, individuals who do not require financial assistance can purchase home support services privately.

Co-payments and Income Testing

Nova Scotia	<p>Fees apply to home care, unless clients' net income falls within or below the designated provincial income category or they receive income-tested government benefits. The maximum monthly fee charged to clients is decided by the client fee determination process, based upon net income and family size. Clients in Chronic Home Care may be charged an hourly fee for home support, personal care and family relief services provided by home support workers/continuing care assistants. Clients receiving home oxygen services are assessed a monthly fee. No fees are charged for nursing services or personal care services provided by registered nurses or licensed practical nurses.</p>
Prince Edward Island	<p>The co-payment for home support services was removed in 2007. There are no direct fees for professional services, but clients must pay the cost of medications, supplies and equipment required for care.</p>
Newfoundland and Labrador	<p>There is no income testing for those requiring professional services or short-term acute home support. To receive home support services, a financial assessment is required. The income threshold varies according to disability and marital status. There may be a co-payment for home support services. Eligibility for supplies, medication and equipment is also means tested except for programs under the 2004 Accord. A limited amount of health care supplies and equipment is provided to home care recipients. Clients may be eligible for the Newfoundland and Labrador prescription drug program. Palliative care is not means tested and is provided for up to a month.</p>
Northwest Territories and Nunavut	<p>There is no income testing and no charges. Supplies, equipment and medication may be funded through a variety of sources including user pay, Non-Insured Health Benefits, extended benefits or private insurance.</p>
Yukon	<p>There is no income testing, nor are there direct fees. Clients must pay for supplies and equipment but may obtain assistance. The costs are covered for palliative care or if you are over 65 years of age, or if a person is registered in the Chronic Disease Program (through Yukon Extended Care benefits). The Non-Insured Health Benefits for First Nations provides some equipment and funding assistance.</p>
<p>Source: Canadian Home Care Association. <i>Portraits of Home Care in Canada 2008</i>. (Ottawa: Canadian Home Care Association, March 2008).</p>	

Appendix Four

Services Not Offered Through Home Care

British Columbia	Nurse practitioner, physician, pharmacy, speech and language pathology
Alberta	Nurse practitioner, physician, pharmacy
Saskatchewan	Nurse practitioner; speech and language pathology; physician services; social work, pharmacy, respiratory, dietetics; services may be provided through regions
Manitoba	Nurse practitioner, speech and language pathology, physician services, pharmacy, dietetics
Ontario	Physician (home visits are allowed but are restricted under the fee schedule), pharmacy
Quebec	All services appear to be funded
New Brunswick	Nurse practitioner (physicians reimbursed for services provided to Extra-Mural Program clients)
Nova Scotia	Nurse practitioner, physiotherapy, occupational therapy, speech language pathology, social work, dietetics, physician services, pharmacy
Prince Edward Island	Speech and language pathology, respiratory therapy, nurse practitioner or physician services
Newfoundland and Labrador	Newfoundland and Labrador does not fund physician or pharmacy through home care but does fund all other services, including speech and language pathology on a limited basis
Yukon	Nurse practitioner, respiratory therapist, dietetics, physician, pharmacy, self-managed care
Northwest Territories	Respiratory therapy, self-managed care
Nunavut	Nurse practitioner and physician services, pharmacy, respiratory
Source: Canadian Home Care Association. <i>Portraits of Home Care in Canada 2008</i> . (Ottawa: Canadian Home Care Association, March 2008).	

Appendix Five

Coverage of Drugs, Supplies and Equipment

	British Columbia	There is help for drug coverage through provincial programs such as <i>Fair Pharmacare</i> . The first two weeks of supplies are provided at no charge to post-acute home care clients. Palliative medication and supplies are given to clients receiving end-of-life services through the <i>Palliative Care Benefits Program</i> . Home care clients are responsible for equipment rentals but are assessed for aids if on a community rehabilitation program.
	Alberta	Supplies, equipment and medication are paid for by a mix of public and private funds.
	Saskatchewan	Supplies, equipment and medication are paid for by a mix of public and private funds.
	Manitoba	Supplies, equipment and medication are paid for by a mix of public and private funds.
	Ontario	The home care client is eligible to receive pharmaceuticals that are listed on the provincial formulary. Community Care Access Centres provide some supplies and equipment.
	Quebec	Medical supplies, drugs and equipment are funded by various public agencies (health and social services agency [CSSS], Régie d'assurance maladie du Québec and fiduciary establishments).
	New Brunswick	<i>Extra-Mural Program</i> clients are required to use third-party insurance for drugs wherever possible. If the client has no insurance, the program covers drugs directly related to the client condition. Long-term care and Family and Community Services clients may receive assistance with drugs, supplies and equipment through social assistance or through the Pharmacare program for seniors.
	Nova Scotia	Medical supplies used during the nursing visit are provided, but all other medical supplies are the responsibility of the client. The client is also responsible for providing medical equipment. Medications are provided at no charge to Acute Home Care patients to a maximum combined cost for services and supplies of \$4,000 per month. Services for chronic care should not exceed the cost of equivalent care in a long-term care facility.

Coverage of Drugs, Supplies and Equipment

Prince Edward Island	Until May 2008, clients had to pay the cost of medications, supplies and equipment required for care. In that same month, the <i>Palliative Home Care Drug Program</i> was introduced, which provides drug coverage for pain and symptom management to those who wish to spend their last days in the location of their choice, including at home.
Newfoundland and Labrador	Clients are subject to a means test before being eligible to receive supplies and equipment, unless the individual is on the short-term acute care or end-of-life program. Medications are provided only for those on the acute home care and end-of-life program, and those eligible for the province's prescription drug program.
Northwest Territories	Supplies, equipment and medication may be funded through a variety of sources, including user pay, non-Insured Health Benefits, extended benefits programs or private insurance. Some regions have equipment available on loan.
Nunavut	Supplies, equipment and medication may be funded through a variety of sources, including user pay, non-Insured Health Benefits, extended benefits programs or private insurance. Some regions have equipment available on loan.
Yukon	Supplies, equipment and medication may be funded through a variety of sources, including user pay, non-Insured Health Benefits, extended benefits programs or private insurance. Some regions have equipment available on loan.

Sources: Canadian Home Care Association. *Portraits of Home Care in Canada 2008*. (Ottawa: Canadian Home Care Association, March 2008). // Government of Prince Edward Island. "Province Announces Details of New Palliative Home Care Drug Program." News release, May 13, 2008. Retrieved January 26, 2009, at <http://www.gov.pe.ca/news/getrelease.php3?number=5721>.

Appendix Six

Limits to Care Provision

British Columbia	There are no maximum limits set. Care is given based on assessed need.
Alberta	The regions were responsible for setting limits, but as of the spring of 2008, Alberta centralized its health administration; therefore, it is expected that one standard will apply to the whole province.
Saskatchewan	Saskatchewan has no official limits; the regions generally encourage a move to a long-term care facility when the costs of home care services reach the level of facility care.
Manitoba	Public funding is offered until costs approximate the cost of placement in a long-term care facility.
Ontario	Personal support/homemaking services are provided up to a maximum of 60 hours per month (or 80 hours in the first month of service), 120 hours for adults with physical disabilities. Nursing services are provided for up to 28 visits per week by an RN or RPN; or 43 hours per week for an RN; or 53 hours per week for an RPN; or 48 hours per week by a combination of RN and RPN.
Quebec	Public funding is offered until costs approximate the cost of placement in a long-term care facility.
New Brunswick	Home support is limited to 215 hours per month, and the services provided through the <i>Extra-Mural Program</i> will not exceed those in facility-based long-term care.
Nova Scotia	Services for chronic care should not exceed the cost of equivalent care in a long-term care facility.
Prince Edward Island	Home care services cannot exceed three visits or 28 hours a week, unless special permission is obtained.
Newfoundland and Labrador	There are no limits for professional services, but these services cannot be accessed after hours and there is no provision for emergency response. Home support services are limited by a financial ceiling of \$2,707 per month for seniors and \$3,875 per month for adults with a disability.
Nunavut	There are no maximum limits set. Care is given based on assessed need.

Limits to Care Provision

<p>Yukon</p>	<p>The maximum number of home support hours per client is 35 per week. Services are limited to twice daily visits by professional staff. The total cost of care cannot exceed the cost of care in a long-term care facility.</p>
<p>Source: Canadian Home Care Association. <i>Portraits of Home Care in Canada 2008</i>. (Ottawa: Canadian Home Care Association, March 2008).</p>	

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