

Health Starts at Home:

VON Canada's Vision for Home and Community Care

Report



Touching Lives Since 1897
Au coeur de la vie depuis 1897

VON Canada (Victorian Order of Nurses) is proud to put forward our vision for home and community care in Canada. We are the country's largest non-profit organization dedicated to home and community care, providing more than three million home visits a year. With more than 110 years of experience, we have impressive credentials when it comes to this vital and essential part of our health care system.

At VON Canada we see home and community care as a key element of Canada's health care system, and 78% of Canadians agree that a stronger health care system depends on a better developed home and community care system.¹

Vision statements are about the future, and while nobody can accurately predict it, we do know about some trends that will have a huge impact on health care in Canada:

- Our population is aging and is becoming more diverse.
- We are increasingly reliant on new technologies.
- We want to receive care and services in our homes.
- More than one third of Canadians has a chronic disease. Chronic disease is responsible for 60-80% of total medical costs in Canada.

Our vision reflects our rich experience and intimate knowledge of the sector and the health and social needs of Canadians. It is also the result of a literature review and consultations with clients, caregivers, the VON family and policy and health care leaders. It addresses some of the major issues facing the home and community care sector and reflects what VON Canada staff and volunteers see everyday: people at risk in their homes because they do not have access to appropriate or sufficient care and services. This is not just a crisis of the individual, it affects the family, friends and others who care for these vulnerable people. Family and friend caregivers are increasingly expected to shoulder more responsibility for their loved ones, with few resources and little recognition of their efforts.

We also must tackle the challenges of funding home and community care adequately and support the professionals, volunteers, families and friends who provide so much essential care.

Our vision also addresses disease prevention and health promotion and how to integrate better home and community care into the broader health care system. There is so much we can do in homes and communities to keep people healthy and well – and out of over-crowded emergency rooms, hospitals and long-term care homes. It is clear that investments in home and community care can help reduce ballooning health care budgets that threaten the sustainability of the system overall.

Implementing the VON Canada vision for home and community care will not be easy, but through the leadership of governments, and in partnership with the health and social sectors, Canadians and communities, we are confident that these words can be transformed into action.

Judith Shamian, President & CEO, VON Canada

Acknowledgments

VON Canada would like to thank everyone who helped inform and shape this paper. Specifically, we are grateful to members of VON Canada's Community and National Boards, VON Canada staff, clients and caregivers, health and policy leaders and survey participants for taking the time to share their thoughts and expertise about home and community care in Canada. We hope you are pleased by the extent to which your input has contributed to VON Canada's vision of home and community care for Canada.

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Executive Summary

BACKGROUND

In recent years, Canada has seen a surge in demand for home and community care services. Sadly, this increase in demand has not been met with corresponding investments in the sector. Although jurisdictions have taken steps to improve the delivery of services in homes and communities, on a national level home and community care systems remain inadequate, fragmented and inaccessible to many.

There is an urgent need for an enhanced approach for home and community care in Canada: it is what Canadians have said they want and it is also an essential step toward ensuring the sustainability of our health care system. At VON Canada, we believe this can best be achieved through a national approach to home and community care.

HEALTH STARTS AT HOME: VON CANADA'S VISION FOR HOME AND COMMUNITY CARE

Considering the current state of home and community care across the country and the fact that an increasing number of Canadians will be relying on the sector in the future, it is critical that a comprehensive, national approach to home and community care be put in place. As an acknowledged leader and innovator in home and community care, VON Canada proposes a new vision of home and community care – one that calls upon governments and other concerned parties to address the challenges facing the sector, capitalize on opportunities, and ensure Canadians' home and community care needs are met now and into the future.

To transform VON Canada's vision into reality, immediate action must take place across the following six strategic areas:

- Health Human Resources
- Integration of Care and Services
- Information Communication Technology
- Chronic Disease Prevention and Management
- Caregiving
- Investing in Home and Community Care

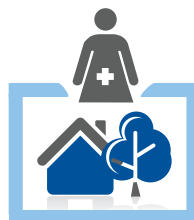
VON Canada's vision for home and community care identifies challenges and opportunities in each of these key areas and makes recommendations so that we can move forward. Although the recommendations are targeted

primarily at governments and health and social leaders, the realization of VON Canada's vision will require all those responsible for shaping health care in this country – governments, health and social sectors, communities, and Canadians themselves – to work together.

SUMMARY OF RECOMMENDATIONS

A robust and accessible home and community care system that is integral to our publicly-funded health care system will help Canadians age at home and keep people well and out of emergency rooms, hospital beds, and long-term care institutions.

The following recommendations represent a starting point to help Canada build a comprehensive, flexible and integrated system of care and supports to help Canadians remain independent and healthy in their homes.



1. HEALTH HUMAN RESOURCES (HHR)

To maximize HHR capacity, better address the needs of Canadians and increase access to high quality care, VON Canada calls upon governments at all levels to work with stakeholders to:

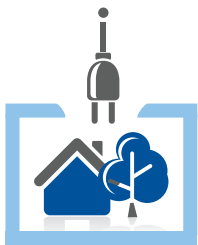
- Pay health care workers who provide care in the home and community the same compensation as those who work in institutions and other health care settings.
- Establish pan-Canadian education standards for unregulated workers, and practice competencies and guidelines for regulated and unregulated workers.
- Develop, fund, and implement recruitment and retention strategies specifically designed for the home and community care sector, for both paid staff and volunteers.
- Increase access to educational and training opportunities for staff and volunteers.
- Base HHR forecasting on the expressed *needs* of home and community care clients.
- Develop electronic tools to ensure that innovations and best practices for the home and community care sector are shared among workers.
- Expand current HHR data collection efforts, starting with unregulated workers in both the public and private sectors, as well as volunteers.



2. INTEGRATION OF CARE AND SERVICES

VON Canada's vision includes an integrated model of health and social care and calls upon governments at all levels, in partnership with other stakeholders to:

- Evaluate the various national and international models of home and community care to determine which model would best serve Canadians. Models should be evaluated based on access, quality, cost-effectiveness and a client-centred approach.
- Examine how best to integrate social services with home and community care, while ensuring that social services are not being absorbed and redefined by the acute care lens.
- Develop policies and delivery and funding models that encourage and support communities to undertake integrated planning and delivery of care and services across sectors.



3. INFORMATION COMMUNICATION TECHNOLOGY

VON Canada endorses the recommendations recently outlined in the report *Integration through Information Communication Technology for Home Care in Canada* (CHCA, March 2008). In particular, VON Canada suggests that all levels of government work together to:

- Create and implement a technology strategy for the home and community care sector. Developed in partnership with the sector, a key goal of this strategy should be better integration among and between sectors and at a minimum include the following steps:
 - Broaden Canada Health Infoway's work on electronic health records (EHRs) to include the home and community care sector and create a comprehensive EHR connecting all points of care within the next 10 years.
 - Purchase or develop electronic clinical systems for use in the home to capture and monitor clients' health information.
 - Facilitate the development and purchase of technology in the home that directly benefits clients and their providers.



4. CHRONIC DISEASE PREVENTION AND MANAGEMENT

To help prevent illness and better manage chronic disease, VON Canada recommends that all levels of government partner with stakeholders to:

- Accelerate the implementation of comprehensive chronic disease prevention and management strategies, while maximizing the contributions of all sectors and providing sufficient funding and resources. At a minimum, the following steps should be taken:
 - Provide incentives to employers to proactively support the health of their employees through healthy work policies.
 - Work with educators to ensure school curricula (starting at pre-school) emphasize the importance of a healthy lifestyle and highlight the consequences of chronic disease.
 - Revise curricula for all health care workers to include training on chronic disease prevention and management strategies.
 - Develop a national communications strategy to educate the public on physical and mental health and chronic conditions.
 - Fund targeted programs to work with "at-risk" populations and communities to prevent and better manage chronic disease.
 - Promote the use of client-centred models of care that acknowledge the diverse range of resources available in communities to promote health and manage chronic disease.
- Enhance the role of the home and community care sector in the prevention and management of chronic disease by:
 - Adapting all chronic disease prevention and management resources for the home.
 - Providing clients and caregivers the option to choose the services that best address their needs.
 - Working with public health and primary health care to provide tailored health promotion programs and activities to people in their homes and communities.
 - Implementing flexible community funding models that support "non-traditional" in-home service delivery.



5. CAREGIVING

To recognize caregivers as part of the health care team and to ensure that their caregiving role should not result in undue physical, mental, or financial

hardship, VON Canada recommends that all levels of government partner with stakeholders to:

- Assess the needs of caregivers and provide them with services, education, training and information.
- Convene an expert panel to look at the financial security of caregivers so that their role as caregiver does not result in personal financial loss and insecurity.
- Create an awareness campaign to recognize the contributions and needs of caregivers.



6. INVESTING IN HOME AND COMMUNITY CARE

To ensure that all Canadians have access to comprehensive home and community care supports, VON Canada

recommends that federal, provincial and territorial governments:

- Establish a federal, provincial, territorial working group to develop and implement a comprehensive, national approach to home and community care. This universal program should be governed by principles enshrined in legislation to ensure all Canadians have equal access regardless of their circumstances.

- Increase public investment in home and community care. As a starting point, Canada should double the proportion of Gross Domestic Product (GDP) devoted to the sector immediately, to bring Canadian investment in home and community care up to the Organisation for Economic Co-operation and Development (OECD) average of 0.35%.

CONCLUSION

The Honourable Tommy Douglas, referred to as “the father of Medicare” and voted in 2004 as the Greatest Canadian, envisioned Medicare being implemented in two phases. The first phase was to publicly finance the medical system and the second phase was to deal with the delivery of health care services beyond acute care. While the first part of this vision has been put in place, decades later the second part remains to be completed.

Despite its exclusion from the Canada Health Act, research and experience tells us that home and community care plays an essential role in maintaining and enhancing the health of Canadians and the sustainability of the health care as a whole. What is currently in place, however, does not meet the needs of Canadians today, and demographic and other trends suggest that it will fall far short of meeting future needs. The time has come for governments to work together to put in place a comprehensive home and community care system that responds to the needs of all Canadians so that they can give the best of themselves to their families, communities and country.

Introduction

American actor George Burns once said, “I look to the future because that’s where I’m going to spend the rest of my life.” This simple idea is at the heart of VON Canada’s vision. In thinking about health care, we too often focus on today’s immediate challenges, without looking further into the future to determine how best to capitalize on opportunities to enhance the overall quality of our lives. A new approach to home and community care is one key way to help correct this short-sightedness.

If we want an effective health care system, we need an integrated, comprehensive home and community care system, dedicated to supporting the ongoing health and social needs of Canadians. It is well known that providing comprehensive long-term home care can reduce or prevent admissions to hospitals and long-term care institutions.² In addition to improving the quality of life of Canadians, providing care in homes and communities is often more cost-effective and reduces pressures on other parts of the health care system. Home and community care services help keep people out of emergency rooms, alternate level of care (ALC) beds, hospital beds and long-term care institutions.

Canada has seen a surge in demand for home and community care services. There are several factors involved, two of which are the aging population and the restructuring of health care services; care once delivered in hospitals and other institutions is now delivered in the home or in communities.

Sadly, the increased demand for home and community care services has not been met with corresponding investments. Although jurisdictions have taken steps to improve the delivery of services in homes and communities, three fundamental flaws with the system remain:

- Acute and post-acute medical needs, by their urgent nature, are given priority over personal, on-going needs that can be met in the home or community.
- Home and community care and services are excessively rationed, leaving many ineligible for care and services. Clients who receive care often see their services discontinued before their needs have been adequately addressed.
- Access to care is not equitable. For the most part, the care and services you receive depend on where you live and what you can afford.

Taken together, these failings are preventing the home and community care sector from reaching its full potential in contributing to Canadians’ individual health and well-being, as well as to the sustainability and effectiveness of the health care system as a whole.

VON Canada’s vision to transform home and community care focuses on six strategic areas:

- Health Human Resources
- Integration of Care and Services
- Information Communication Technology
- Chronic Disease Prevention and Management
- Caregiving
- Investing in Home and Community Care

The following paper provides an overview of home and community care in Canada, outlines the flaws and implications of the current approach, and proposes recommendations in each of the six key areas to help decision-makers take action. VON Canada is open to collaborating with all sectors to further discuss, explain, and move these recommendations forward.

Although the recommendations are targeted primarily at governments and health and social leaders, realizing this vision will require all those responsible for shaping health care in this country – governments, health and social sectors, industry, communities, and Canadians themselves – to work together.

Context



Since the creation of Medicare in the 1960s, Canada has undergone a number of profound demographic, social, economic and technological changes.

- **Demographic change:** Canadians are living longer and have fewer children today than in the 1960s. The census indicates that 13.7 % of Canadians are senior citizens, and only 17.7 % are under the age of 15 – the lowest number in Canada’s history. It is estimated that, by 2015, there will be more seniors than children.³ Demand for home and community care increases with age. Seniors are the primary users, particularly those aged 75 and over.⁴ Most seniors prefer to age at home, retaining their independence rather than moving to nursing homes and long-term care facilities. Demographic trends, therefore, point to a growing demand for home and community care.

- Canada is also more culturally, linguistically and ethnically diverse than it was in the 1960’s. Members of visible minority groups make up approximately 16.2% of the total population, up from 9.4% in 1991. This number is expected to increase to 20% by 2017.⁵ This diversity must be reflected in home and community care planning.

- **Social change:** Families are different than they were in the 1960s. The

2006 Census shows a significant increase in childless couples, single-parent households and people living alone. In 1941, only 6% of Canadians lived in one-person households. Today, this number has climbed to 26.8%.⁶ Far more women have entered the workforce, and this too has had implications on caregiving responsibilities for younger and older family members.

- **Economic change:** Although generally considered to be a wealthy nation, a significant portion of Canada’s population lives below the poverty line. While the percentage of seniors with low incomes has decreased since the 1980s, 7% of seniors in Canada remain economically vulnerable.⁷ Income is one of the most important determinants of health and affects Canadians’ access to home and community care supports.

- **Technological change:** Technology has had a profound effect on every part of Canadian society over the last 40 years, including health care. Not only has technology enabled people to live longer and receive a higher quality of care, it has also allowed people to receive more care and services in their homes, such as chemotherapy and dialysis. Technology has also given individuals access to a wealth of health information, empowering many Canadians to take a more active role in their health and well-being. Technology will be a key enabler for the home and community care sector in the coming years.

It is clear that much has changed in Canadian society since the 1960s. It’s equally clear that without significant reform, the health care system will continue to struggle to meet the future demands of Canadians. Canadians are committed to

**BY THE NUMBERS:
CANADA’S AGING
HEALTHCARE WORKFORCE:**
Similar to the rest of the population, Canada’s health care workers are aging. For example, in 2005 the average age of an RN in Canada was 44.7 years compared to 41 in 1994.

CIHI. (2007). *Health care in Canada 2007*. Ottawa, ON: Author.

publicly-funded, universal health care, and they want reforms that will strengthen and improve it.⁸ If public confidence in the health care system is to be maintained, all stakeholders must work together to ensure that the needs of all Canadians are being effectively addressed.

OVERVIEW OF HOME AND COMMUNITY CARE

Approximately 900,000 Canadians access home care on a regular basis.⁹ From 1995-2002, the number of Canadians receiving home care increased by over 60%.¹⁰ Indeed, home care is the fastest growing sector in health care and demand will continue to grow. It is predicted that between 1996 and 2046, the number of people needing home care will double.¹¹

Canadians depend on the home and community care sector to help them live, heal, age and die in the comfort of their homes. Home and community care encompasses a wide range of services delivered at home and throughout the community to people at all ages and stages of life in need of medical, nursing, social or therapeutic treatment and who require assistance with daily activities and tasks.

Providing care and services in a person's home is much different than attending to people's health needs in an institution. A variety of providers – paid and unpaid, regulated and unregulated – are involved in service delivery. Two important groups include:

- **Family and friend caregivers** – Providing the majority of care at home, caregivers act as advocates for their loved ones, and provide wide-ranging care and support, including the organization of resources and community supports, transportation and medicine administration.
- **Volunteers** – Providers of invaluable support to home care staff, clients and their caregivers. In partnership with community organizations, they deliver a number of services and supports to people in their homes and strengthen the capacity of the formal home and community care sector. Programs such as Meals on Wheels and volunteer visiting are often only available because of a dedicated volunteer base.

Both of these groups help people with on-going care needs live independently in their homes and communities, and complement the essential care provided by paid staff, such as nurses and home support workers and personal support workers (also referred to as health care aides).

Despite the strong demand for home and community care in Canada, funding and planning for the sector have not kept pace. Canada's spending on home care pales in comparison to many of the Organisation for Economic Co-operation and Development (OECD) countries.¹²

Although there have been a number of seminal health reform documentsⁱ calling for an expanded approach to home and community care, there has been little action at the national level to ensure equitable access to comprehensive, high quality home and community care. There are several reasons for this:

- Home and community care is not protected by the principles of the *Canada Health Act* (CHA) and as a result, has been poorly funded and marginalized within the health care system.¹³
- While all provincial and territorial governments do provide or fund some home and community care programs, they are not required to do so by the CHA.
- Each province and territory has its own definition of what home care entails, and designs its own system based on its priorities and availability of resources.¹⁴

As a result, across the country, and even within jurisdictions, there is a patchwork of services and many Canadians lack access to home and community care. Some jurisdictions in Canada have made improvements in the delivery and coordination of home and community care and services, but on a pan-Canadian level, home and community care remains fragmented and inaccessible to many.¹⁵

In an effort to reconcile these disparities, through the 2003 Accord on Health Care Renewal and the subsequent 2004 Ten Year Plan, provincial First Ministers established common standards for three short-termⁱⁱ home care needs: acute care, mental health, and end-of-life care. However, these standards apply only under very specific circumstances and time frames, and are not relevant for many Canadians whose home care needs are very different from those who were targeted by the First Ministers. Clearly, there is a disconnect between what resources and supports are available through government-funded home and community care, and what Canadians want and need from the system to help them remain healthy and safe in their homes.

ⁱ A number of health reports have called for an expanded approach to home and community care, including: National Conference on Home Care, 1998; Building on Values: The Future of Health Care in Canada, 2002; and Fixing the Foundation: An Update on Primary Care and Home Care in Canada, 2008.

ⁱⁱ As a result of the First Ministers Meetings in 2003 and 2004, Canadians have been promised access to a minimum of two weeks of home care for acute care and mental health needs, as well as end-of-life care.

THREE FUNDAMENTAL FLAWS

Many of the shortcomings of the current home and community care sector flow from three overarching flaws:

- Acute and post-acute medical needs, by their urgent nature, are given priority over on-going, personal “non-medical” needs.
- Home and community care and services are excessively rationed, leaving many ineligible for care and services. Clients who receive care often see their services discontinued before their needs have been adequately addressed.
- Access to care and services across Canada is inequitable.

Acute and post acute medical needs, by their urgent nature, are given priority over on-going, personal “non-medical” needs. Long-term home supports that help people remain independent are undervalued. For example, help with bathing and dressing, food preparation and housekeeping and home maintenance are key to keeping the chronically ill, the disabled, the frail and elderly, and those suffering from long-term mental health issues independent and out of institutions.

BY THE NUMBERS: THE IMPORTANCE OF LONG-TERM HOME SUPPORTS

Home supports play a major role in the cost-effectiveness of long-term home care. In a study conducted by Hollander (2001), approximately 80% of expenditures for long-term home care for people with high level needs (i.e. people with similar needs to those in residential care) were for home support services, and the remaining 20% were for services performed by regulated staff.

Hollander, M. (2001). *Substudy 1: Final report of the study on the comparative cost analysis of home care and residential care services*. Victoria, BC: National Evaluation of the Cost-Effectiveness of Home Care.

were related to a greater need for acute care and residential care after services were terminated.¹⁶

Another Canadian example that illustrates the importance of home supports is the Veterans Independence Program (VIP). The VIP is a national home care program provided by Veterans Affairs Canada to help eligible veterans age independently in their homes and communities. In conjunction with the public system, this innovative and flexible program provides a range of services, including snow shoveling, personal care services, and health and social supports. The VIP has benefited both clients and the health care system by giving people flexibility and choice, and substantially reducing the need for more costly institutional care.

Almost all jurisdictions recognize the need to provide *some* level of support to Canadians who require help with personal care, but the types of support offered, or the amounts available, are often inappropriate and insufficient to meet a wide range of needs. That being said, some jurisdictions are working hard to correct this imbalance by investing heavily in “aging at home” strategies that emphasize long-term, practical supports to help Canadians with daily living. However, for the most part, policy makers do not fully appreciate the important link between “non-medical” home supports and health when making policy and funding decisions. A disconnect remains between what services are offered by governments and what Canadians need to stay healthy and safe in their homes.

As well, the growing demand for services in Canada, combined with insufficient funding and limited health human resources, has led to the **excessive rationing of care and services**. Examples of rationing of care and services include restricting the number of visits or services for a client, creating waiting lists for home support services or community support services such as adult day programs, and relying too heavily on unpaid family, friends and volunteers to provide services and care.

When clients do not receive the care they need to stay at home, they turn to institutions – frequently emergency rooms – for essential services. This costs the health care system much more in the long run. Other clients may decide to go without the care they need, which has serious consequences on their health and well-being. Some are left with no other option but to prematurely enter institutions, such as long-term care facilities or nursing homes, even though they may not require this level of care.



Finally, **access to care and services across the country is highly inequitable.** In 2003, 35% of Canadians expressed dissatisfaction with their access to home and community care.¹⁷ Geographic location is one of the most important barriers – especially for the 20% of Canadians living in rural and remote areas.¹⁸ It is important to note,

however, that the availability of home and community care and services in a given region does not guarantee accessibility to all who may need it. Language and cultural barriers and general unfamiliarity with the system can be serious obstacles to accessing home and community care.

Perhaps most importantly, the high cost of home care

services in this country makes them unattainable for many low-income earners. Many of the services that were previously provided in hospitals at no cost are no longer available. And although “medically necessary” according to the *Canada Health Act*, these services, because they are now provided in the home or community, are not always fully covered by provincial and territorial health care plans. For example, medications or physiotherapy services that would have been covered if a person was receiving care in a hospital may or may not be covered if that person is receiving the same care in their home.

The trend to provide more health care in the home and community – without corresponding support – means that individuals and families are forced to shoulder much of the cost for certain services. Clients may be required to pay user fees for select services, such as personal and community supports, medical supplies or adaptive equipment.¹⁹ This proves to be difficult, if not impossible, for many clients – often those who need the services the most: people with disabilities who are unable to work, seniors living on fixed incomes and pensions, immigrant seniors, Aboriginal seniors, and seniors living alone. For those who cannot afford to pay for select support services, they either go

**BY THE NUMBERS:
END OF LIFE CARE**
Access to quality end-of-life care in the home is an area of particular concern. Although the majority of Canadians would prefer to die at home than in a health care institution, 60% of deaths still occur in a hospital.

Quality End-of-Life Care Coalition of Canada. (2008). *Hospice palliative home care in Canada: A progress report*. Ottawa, ON: Author.

without or look to provider organizations (often not-for-profit organizations) for help to cover the cost.

BROADER IMPLICATIONS

On any day, in many parts of the country, one out of five hospital beds is occupied by someone who could receive care elsewhere.²⁰ These patients, called Alternate Level of Care (ALC) patients, are often frail, elderly people who have received acute care treatment. They no longer require that same level of care, but need other kinds of supports, such as a long-term care, palliative care, supportive housing, or home and community care which are not available. Since the type of care they require is not always available, they are often left waiting in hospital beds. This situation presents grave challenges for two reasons:

- Patients must remain in a hospital until appropriate care is available, thereby affecting their quality of life and even health outcomes, as they are unnecessarily exposed to hospital infections, and over time lose some of their functional ability.

**BY THE NUMBERS:
ALTERNATE LEVEL OF
CARE (ALC) PATIENTS**
The costs of ALC patients to the system are significant. In 2004-2005, ALC patients accounted for 8.7% of the total in-patient days, with an average length of stay five times greater than the overall in-patient average length of stay (36.1 vs. 6.5 days)

Jokovic, A., Baibergenova, A., Baldota, K., & Leeb, K. (2006). CIHI survey: Alternatives to acute care. *Healthcare Quarterly*, 9(2) 2006: 22-24

- The number of ALC patients occupying hospital beds leads to decreased acute care capacity, which in turn contributes to the overcrowding of emergency rooms, decreased capacity to perform surgeries (due to lack of recovery beds), staffing concerns and patient flow inefficiencies.

The growing number of ALC beds is symptomatic of the lack of capacity and integration in our health care system. Canadians require more post-hospital community-based options, including enhanced home and community care. With

the proper supports, many ALC patients could be cared for at home, helping to ease the pressure on hospitals and long-term care facilities.

In addition to resources, collaborative mechanisms between health providers across care settings are required to enhance patient flow and alleviate ALC pressures. Some hospitals and community partners are working together to increase home and community care services (especially

personal and home supports), but much more remains to be done. For the majority of Canadians, receiving care at home is a cost-effective substitute to receiving care in institutions.²¹ It alleviates pressures on other parts of the health care system, and it is the expressed preference of most Canadians.

If home and community care can help people leave hospitals sooner, it can also keep people healthier so they will not need hospital care in the first place. We have already discussed the preventive and maintenance roles home supports, such as housekeeping and meal preparation, play in keeping people healthy and independent at home. Additionally, through health promotion and disease prevention efforts, home and community care can prevent or delay the need for institutional-based care. VON Canada offers a number of resources and programs that encourage Canadians to remain healthy and active members in their communities.

For example, the Seniors Maintaining Active Roles Together (SMART) program provides older adults the opportunity to participate in volunteer-led fitness classes within their homes and communities. Not only does SMART increase participants' functional fitness, but it also decreases their isolation and contributes to their mental and physical well-being.

Health promotion and prevention efforts are particularly important when it comes to chronic diseases, which already account for a huge proportion of medical costs in Canada, and will become even more of a burden as the Canadian population ages.

QUOTE FROM A SMART PARTICIPANT

"I have lost 15 pounds. I feel healthier. I have asthma, and I can breathe better. I feel more trimmed down. I think it's a mental and physical thing for me."

Boris, J., Jones, G., Lauzon, N. (2004). *Evaluation of the VON Canada SMART program*. Canadian Centre for Activity and Aging.

VON Canada's Vision for Home and Community Care: Transformation Based on Six Key Areas of Change

VON Canada has a vision for home and community care that would see all Canadians living independently and enjoying a high quality of life in their homes and communities for as long as they choose. Recognizing the diverse personal, social, and clinical needs of the population, our vision is focused on the provision of customized care that promotes the health and well-being of people of all ages and stages of life. We firmly believe that a flexible system that integrates health and personal/home supports with community programs, and that harmonizes the valuable contributions of all providers – including volunteers and family and friend caregivers – is the best way to help Canadians help themselves to a healthier, happier lifestyle in their homes, where they want and need to be.

The vision for home and community care that VON Canada proposes will help meet the changing needs of our population and address the fundamental flaws in Canada's current home

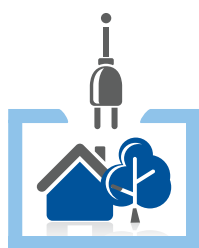
and community care system. To move this vision from words to reality, immediate action must take place across the following six areas of home and community care:



Health Human Resources



Integration of Care and Services



Information Communication Technology



Chronic Disease Prevention and Management



Caregiving



Investing in Home and Community Care

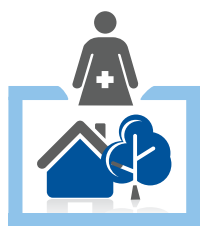
While taking action across these six areas, VON Canada also recognizes that an improved home and community care system depends on the *social determinants of health* and the *social capital* available to individuals, their families, and their communities. It is now broadly accepted that factors such as social environments and social support networks play a fundamental role in shaping the health of individuals and communities. Research indicates that only 25% of the population's health is attributable to the reparative work of the health care system, while the other 75% is attributable to the social determinants of health.²² To maximize the benefits of home and community care, the circle of care must be broadened to reflect all of the factors that shape Canadians' health, including those outside the formal health care sector.

Educational and religious institutions, support networks – such as family, friends and neighbours – not-for-profit agencies and other community resources shape and sustain healthy communities. Often referred to as *social*

capital, these resources help citizens remain engaged in life and socially connected. This social capital contributes to the health and well-being of individuals and, by extension, to that of communities. If properly supported and integrated, these elements of our social capital can complement the formal system and help people remain in their homes and communities.

SIX KEY AREAS FOR TRANSFORMATION

The home and community care sector cannot achieve VON Canada's vision alone. The health challenges facing Canadians, as well as the solutions, are a collective responsibility. Governments at all levels and other stakeholders, including groups representing the health, community and social sectors, voluntary and non-governmental organizations, industry, education, professional bodies, the research community and Canadians themselves, need to *understand, support, and/or act upon* the recommendations outlined in the following six key areas.



1. HEALTH HUMAN RESOURCES (HHR)

A Shortage of Health Human Resources in Home and Community Care

In Canada, all health care sectors face significant challenges recruiting and retaining health care providers. The home and community care sector is no exception. Recruiting and retaining qualified people and meeting their evolving educational needs is the number one challenge facing home and community care programs, particularly in rural and remote areas of the country.²³

According to a study conducted by the Canadian Home Care Association (CHCA) there is a perceived shortage of home and community care workers, which, if not

addressed, will see the ratio of regulated staff to consumers fall from 1:37 in 2001 to 1:57 in 2016 and ultimately to 1:100 by 2046. A similar pattern is predicted for support workers. If current trends continue, the ratio of home support workers to consumers will fall from 1:17 in 2001 to 1:25 in 2016 and eventually to 1:45 in 2046. Attracting and retaining enough staff is made more difficult due to the fact that the sector has not traditionally attracted men or younger workers.²⁴

BY THE NUMBERS:
SHORTAGE OF HEALTH HUMAN RESOURCES
The global shortage of health human resources impacts people's access to quality care around the world. The World Health Organization (WHO) estimates a current global shortage of over four million health care workers.

World Health Organization. (2006). *The global shortage of health workers and its impact*. Fact Sheet No. 302.

Home and community care faces a number of HHR challenges - some of which are unique to the sector:

- The workforce is aging and getting smaller, with fewer people being trained to enter the workforce than there are older, retiring workers.
- In some jurisdictions, there is a lack of parity of salaries and benefits between those who work in institutions and those who work in the community.
- Home care providers often have less job security, and a less stable work environment than their counterparts who work in institutions, which can lead to high turnover.

- The workforce faces a variety of personal safety issues that are often difficult to anticipate and address as providers have little “control” over their work environment (i.e., people’s homes).

Home and Community Care Providers

In Canada, service delivery models are a mix of public sector and/or contracts with the private sector, including both for profit and not-for-profit organizations.²⁵ To add to this mix, a variety of different providers work in the home and community care sector, and contribute immensely to the health and well-being of people in their homes. The diversity of providers – from regulated and unregulated staff working in the private and public sectors to volunteers and family and friend caregivers – enriches the home and community care arena while also presenting challenges. Recommendations specific to caregivers are offered later in this document.

Nurses form the largest regulated group of providers. Because of home and community nurses’ clinical expertise, with the help of technology, many Canadians are now able to receive care and treatments at home, which at one time would have required a hospital stay. Grounded in a holistic approach to health, nurses working in this sector understand that social, emotional and clinical factors all need to be addressed to maintain and enhance the health of Canadians and their communities. This comprehensive approach positions them well to address the diverse and changing health and social needs of Canadians.

Personal and home support workers make up the majority of the paid workforce in the home and community care sector. They complement the work of regulated professionals and play a key role in helping vulnerable people stay healthy in their homes and active in their communities – especially those who may not have access to help from friends and family. For family and friend caregivers, support workers represent an essential resource, allowing them to share the responsibility of care and giving them “peace of mind”.²⁶

Two key issues for the unregulated workforce that require immediate attention relate to working conditions and education standards. Although they contribute immensely to people’s care in the home, their working conditions are even less favorable than that of regulated staff. They frequently make little more than minimum wage, with few or no group benefits, especially for non-unionized employees. Secondly, unregulated workers do not often have

clear and consistent educational requirements, and therefore skill sets can vary across organizations and regions. Both issues need to be addressed in order to maximize the contributions of this essential group of providers.

Partly as a result of the shortage of paid staff, the home and community care sector relies heavily on **family and friend caregivers and volunteers** to provide much-

**BY THE NUMBERS:
VOLUNTEERS AND VON
VON, a national not-for-profit home and community care organization, can attest to the value of volunteers. In 2007, a total of 9,016 VON volunteers provided over 417,000 hours of service across Canada.**

Victorian Order of Nurses [VON]. (2008). *VON annual report: 2007-2008*. Ottawa, ON: Author.

needed care and support. However, relying on unpaid providers to support people in their homes over a long period of time is an unsustainable strategy. The number of caregivers and volunteers and the amount of time they are able to devote to caring for others is decreasing due to changing social attitudes and realities. Canada's volunteer force is also changing, with

fewer people providing the majority of service.²⁷ Recruiting and retaining volunteers is becoming increasingly complex, with more people interested in short-term volunteering than committing themselves to long-term positions. This creates a number of challenges for organizations as more and more resources are devoted to attracting volunteers from a shrinking pool.

Given the increasing shift in care to homes and communities, it is essential that health human resource planning devotes considerable attention and resources to improving the working conditions and maximizing the contributions of those who work in home and community care.

Education Preparation and On-going Professional Support/Training

All care providers, whether paid or unpaid, need education and training if they are expected to carry out essential tasks and provide quality care. Paid providers working in home and community care need to be both "generalists" and "experts" to address the variety of care needs found in homes and communities, as well as the growing number of people being discharged from hospitals with complex care needs. Since workers are

providing care in someone's home, and not an institution, the lack of predictability and control adds an extra layer of complexity to the mix. They must also interact with a range of professions, across a variety of health and social care settings. This dynamic working environment requires independent thinkers who are well-educated, adequately mentored, and have sufficient resources to effectively deliver high quality care.

Health human resource planning has been on the national agenda for some time now, with decision-makers at all levels (federal, provincial/territorial and within organizations) devoting considerable energy and resources to solving recruitment and retention challenges. However, little HHR planning has been conducted for home and community care, despite the increasing reliance on its workers and their expertise. The sector would greatly benefit from strategic HHR planning and corresponding investment.

RECOMMENDATIONS

To maximize HHR capacity, better address the needs of Canadians and increase access to high quality care, VON Canada calls upon governments at all levels to work with stakeholders to:

1. Strengthen the HHR capacity of the home and community care sector in the following key areas:

- **Compensation: Pay health care workers who provide care in the home and community the same compensation as those who work in institutions and other health care settings. Nova Scotia offers a good example by bridging the income gap between health care workers across sectors. In conjunction with this recommendation, governments must boost financial support for people on fixed incomes who pay privately for care so that they can afford to pay market rates for the care they require.**
- **Practice Competencies, Guidelines and Education: Working with regulators and educators, establish pan-Canadian practice competencies and guidelines for regulated and unregulated workers, and education standards for unregulated workers. In addition, provide the necessary training and education and monitor work practices.**
- **Recruitment and Retention: Develop, fund, and implement recruitment and retention strategies specifically designed for the home and community care sector, for both paid staff and volunteers.**

- **Education and Training: increase access to educational and training opportunities for students, staff and volunteers. Specific strategies to support this goal include:**

- Increase community-based practicum placements and mentorship opportunities for new graduates
- Fund and develop continuing education initiatives for staff (e.g., develop electronic resources for sharing clinical and professional information)
- Hold regular education sessions for volunteers

2. Develop electronic tools that ensure that innovations and best practices for the home and community care sector are shared among workers. Health Canada should initiate this effort and link with other related electronic resources (e.g., The Canadian Best Practices Portal for Health Promotion and Chronic Disease Prevention).

3. Base HHR forecasting on the expressed needs of home and community care clients so that clients fully benefit from the contributions of the regulated, unregulated, and volunteer sector workforce.

4. Expand HHR data collection efforts through collaboration between the Canadian Institute for Health Information (CIHI) and Statistics Canada. As a first priority, an expert working group should determine how to collect data on unregulated workers active in the public and private sectors, as well as volunteers.



2. INTEGRATION OF CARE AND SERVICES

Canadians generally use a mix of health services and providers that frequently operate in isolation, often unaware of other providers' activities and decisions. This can

lead to fragmentation and a lack of coordination within the health sectors, and also within the broader health care system. For the patient, fragmented systems of care and supports can result in the repetition of tests, unnecessary delays, disruptive flows from one health care setting to another, and, understandably, a feeling of frustration. There are also serious safety risks posed to

patients, such as medication errors due to miscommunication between sectors, providers and patients. The fact that many Canadians are unaware of how to access the full range of resources that exist in their communities is another significant problem.

Canada's fragmented system is particularly challenging for people with on-going care needs, such as those with complex chronic conditions and the frail elderly, as they rely on comprehensive care and supports to properly manage their health and social needs. There is a growing body of evidenceⁱⁱⁱ that argues that integrated delivery systems, designed to meet the needs of particular populations, are not only more efficient, but also more cost-effective.²⁹ VON Canada believes that all Canadians would benefit significantly from better coordinated and integrated systems of care.

Integration of Home and Community Care: A Natural Fit

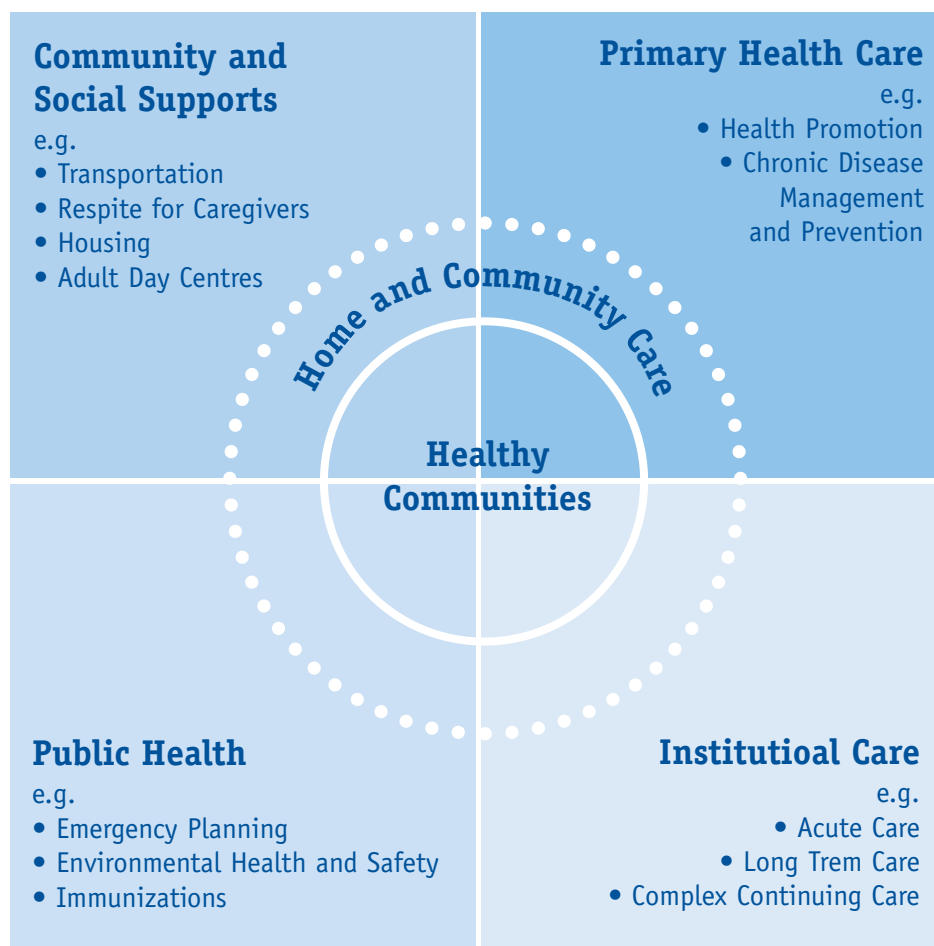
In order to provide clients with seamless care, enhanced integration needs to occur on two levels. There needs to be better integration both within the home and community care sector itself, and also with other health care sectors.

For home and community care, integration of care and services is all the more important because the sector encompasses a broad range of actors, from both within and outside the traditional "health" portfolio in a variety of health care settings across the continuum of care. Home and community care combines health services with community services such as transportation and respite for caregivers – all to the benefit of clients, their families and their communities.

The diagram on the next page demonstrates how the home and community care sector depends on expertise across the full continuum of care to help build healthy communities and healthy people. Unfortunately, the care Canadians receive is not as seamless as it should be, due to the absence of formal mechanisms to facilitate integration among these different sectors, such as system-wide case managers, electronic health records (EHRs), and common assessment processes,.

Recognizing the benefits of integrated systems of care, decision-makers across Canada have undertaken a number of initiatives to enhance coordination among health sectors as well as with the community and social sectors. These include:

ⁱⁱⁱ For more information on the cost-effectiveness of integrated care for people with ongoing care needs, please see the literature review prepared by Dr. Marcus Hollander at www.hollanderanalytical.com



NOTE: Home and community care programs vary considerably across the country. The services listed under “community and social supports” are only examples and could be a part of formal home and community care programs depending on the region.

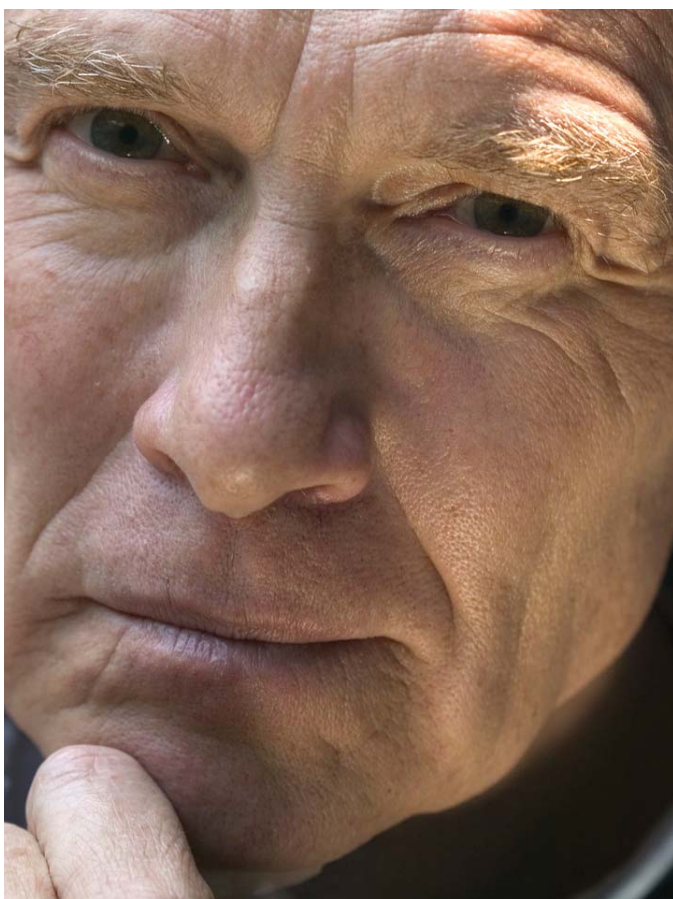
- **Primary Health Care:** aligning home care personnel (including case managers, nurses, therapists and home support) with primary health care teams.
- **Acute Care:** placing home care personnel in acute care settings to support seamless discharge, particularly for ALC patients.
- **Chronic Care:** offering community service options as opposed to hospital-based care (e.g., offering programs in communities to those who have suffered from a stroke).
- **Palliative Care:** providing interprofessional palliative care services to people in their homes, at hospital or in other settings.³⁰

In addition to formal coordination efforts, there are countless informal mechanisms employed by organizations and providers to help facilitate seamless care. However, despite these efforts, the overall system remains

unnecessarily fragmented. Integration activities are generally *ad hoc* and piecemeal, rather than part of a larger comprehensive plan to extend benefits on a provincial/territorial wide basis.

Many other countries, including Germany, Denmark, the United Kingdom, Australia and the United States are experimenting with integrated models of care delivery, primarily to meet the needs of the elderly. This is not surprising given the growing number of seniors, the proportion of seniors with chronic conditions, and their high consumption of health care services.³¹ According to a literature review conducted by MacAdam (2008) regarding integrated systems of care for the elderly, two elements that have proven to be consistently effective are multidisciplinary case management and the provision of a wide range of health and social services.³²

There are numerous challenges associated with implementing integrated models of care at the political, organizational and service delivery level.³³ These



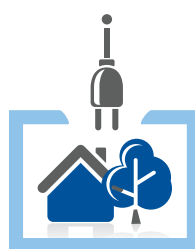
challenges can be overcome, however, with the application of sufficient resources, a concerted effort from providers and decision-makers, and a firm commitment to the end goal: a better quality of life for Canadians and improved system outcomes.

Given the fact that more care and services will be delivered in homes and communities than institutions, it is critical that we maximize collaboration across all care settings. It is for decision-makers to determine whether this is done through well-coordinated systems of care (i.e., current structures/sectors remain the same, but with greatly enhanced collaboration) or fully integrated systems of care (i.e., home and community care becomes a part of primary or continuing care sectors). Further research is needed to understand the benefits and drawbacks of each approach. Secondly, the course of action taken depends on the context of each jurisdiction. Policies need to be adapted to local realities because in the end, integration can only happen with cooperation and leadership, and its success is very much site-dependent.

RECOMMENDATIONS

VON Canada's vision includes an integrated model of health and social care and calls upon governments at all levels, in partnership with other stakeholders to:

1. Evaluate the various national and international models of home and community care to determine which model(s) would best serve Canadians. Models should be evaluated based on access, quality, cost-effectiveness and a client-centred approach.
2. Examine how best to integrate social services with home and community care, while ensuring that social services are not being absorbed and redefined by the acute care lens.
3. Develop policies and delivery and funding models that encourage and support communities to undertake integrated planning and delivery of care and services across sectors so that clients receive seamless care, with the added benefit of reduced duplication and increased efficiencies. For example, governments could provide "integration grants" to local health, social, and community organizations to help them collectively meet the needs of their citizens. Grants should be accessible to all, not limited to organizations that already receive funding from governments.



3. INFORMATION COMMUNICATION TECHNOLOGY

Information Communication Technology (ICT), defined as "all forms of technology used to create, store, exchange and use information in its various forms,"³⁴ is a growing part of Canada's health care system. Until now, the acute care sector has been the focus of most ICT investments, while community-based care sectors, such as home care, have been given too few resources to fully harness the potential of technology. Increased use of ICT could benefit the home and community care sector by:

- Improving access to resources and supports and facilitating the sharing of information and self-management of health conditions. This is particularly important for Canadians who are house-bound with mobility issues or caregiving responsibilities, and for people living in rural and remote areas.
- Using technology to automate some tasks so that

care providers can be more effective and efficient, and share information and enhance collaboration among team members.

- Contributing to the overall integration of the health care system through the adoption of electronic clinical information systems, such as EHRs which can be accessed by providers across care settings.
- Realizing efficiencies and savings. For example, through the use of home telehealth home health nurses may provide 15-20 virtual visits per day with the help of technology versus an average of 5.2 face-to-face visits.³⁵ The cost benefits of home telehealth will continue to increase given escalating gasoline prices and HHR shortages.
- Facilitating consistent data collection to support planning and evaluation activities.

Incorporating ICT in the home and community care sector would help address a number of key challenges related to access to and quality of care, health human resources, isolation of the workforce, support for caregivers, chronic disease management, integration, and data collection. We must invest heavily in technology for the sector if governments intend to honour their commitments to helping Canadians age at home.

Although there are currently pockets of innovation in the sector, they are very much the result of *ad hoc* investments of pilot funding from governments, technology vendors, and home care organizations.³⁶ For the most part, ICT investments in the home and community care sector are dedicated to automating administrative processes, such as scheduling and billing, rather than to measures that would directly benefit the providers of care and their clients.³⁷ For example, clients and their providers would benefit tremendously from accessing electronic health records in the home. However, Canada Health Infoway, the organization responsible for supporting and accelerating the adoption of electronic health records across the country, does not identify the home environment in their implementation plans (despite specifically mentioning most other points of care) – thereby limiting the usefulness of this essential electronic resource. The lack of systematic implementation of ICT across the sector has resulted in missed opportunities for clients and their caregivers, providers and the system overall.

Given the fact that home and community care is, by its

very nature, removed from institutions, innovative use of ICT should be a key priority. At present, providers are working in isolation, in homes where the only ICT available may be a telephone.

RECOMMENDATIONS

VON Canada endorses the recommendations recently outlined in the Canadian Home Care Association report, *Integration through Information Communication Technology for Home Care in Canada* (March 2008).^{iv} In particular, VON Canada suggests the following to all levels of government:

- 1. Create and implement a technology strategy for the home and community care sector. Developed in partnership with the sector, a key goal of this strategy should be better integration among and between sectors and at a minimum include the following key steps:**
 - **Broaden Canada Health Infoway's work on EHRs to include the home and community care sector. The goal should be to create a comprehensive EHR connecting all points of care within the next 10 years.**
 - **Purchase or develop electronic clinical systems for use in the home to capture and monitor clients' health information.**
 - **Facilitate the development and purchase of technology in the home that directly benefits clients (e.g., technology to help them better manage their care) and their providers (e.g., personal digital assistants to capture and share health information).**



4. CHRONIC DISEASE PREVENTION AND MANAGEMENT (CDPM)

It is estimated that at least nine million Canadians are living with at least one chronic health condition – many are seniors.³⁸ With an aging

BY THE NUMBERS: HOME TELEHEALTH
According to Canada Health Infoway, “home telehealth is the application of information and communications technologies to bring health care to the home environment.”

Research suggests that 46% of home health care visits could be completed through telehealth services.

Chae, Y M, J H Lee, S H Ho, H J Kim, K H Jun, J U Won (2001). Patient satisfaction with telemedicine in home health services for the elderly. *International Journal of Medical Informatics*, 2001; 61: 167-173

^{iv} Please see Appendix B for a copy of the report's recommendations.

BY THE NUMBERS: AGING AND CHRONIC DISEASE

More than three quarters of seniors in Canada have at least one chronic health condition.

Health Council of Canada. (2007). *Population patterns of Chronic Health Conditions in Canada*. A data supplement to *Why Health Care Renewal Matters: Learning from Canadians with Chronic Health Conditions*. ON: Author.

emotional and mental well-being and often makes it difficult for them to carry out daily tasks. Treating and caring for people with chronic diseases is also very costly. Alarmingly, chronic disease is already responsible for 60-80% of total medical costs in Canada.³⁹ It is important to point out that chronic conditions are not limited to physical issues, but can also be mental disorders. For example, four of the 10 leading causes of disability worldwide are mental disorders.⁴⁰

BY THE NUMBERS: HEALTH CARE SPENDING IN CANADA

Based on figures from Statistics Canada, last fiscal year (2007-2008), Canadian governments spent \$115.4 billion for health care. Only 4.4 % of this money was spent on preventive care. This translates to less than five cents on the health care dollar. Three-quarters of health expenditures went to medical care (40.9 %) or hospital care (34.2 %) while the balance was for other health services.

Merck Frosst Canada. (2008). Health spending hits \$115 billion in 2007-08. *Health Edition Online*, July 4, 2008.

the health care system as a whole, as providing care in health institutions for many people is often more costly to deliver than in homes and communities.

Many governments recognize that the predominantly reactive approach to chronic disease is not working and have begun to move towards more comprehensive, population-based models of CDPM, where Canadians play a

population, increasing environmental risk factors (e.g., smog) and a propensity for sedentary lifestyles, the prevalence of chronic disease can only be expected to increase. Chronic disease affects people's physical,

In line with Canada's approach to health care, the current home and community care system is focused primarily on responding to short-term acute care needs in the home and is not designed to prevent and manage chronic disease and illness. In Canada, we can treat a person who has a heart attack very well, but we devote insufficient resources to preventing the attack from happening in the first place. As a result, people with chronic conditions spend unnecessary time in emergency departments, hospital beds and long-term care homes. This reactive response is neither ideal for Canadians, nor for

more active role in managing their own health and care. However, progress is slow and incremental, and much of the emphasis is on providing supports in institutional settings. Supports are not often available in people's homes, thereby limiting access to, and the usefulness of, CDPM resources.

Prevention and management of chronic diseases and conditions are vital to improving the health and wellness of all Canadians. Keeping people well, encouraging Canadians to take a more proactive approach to their health, and providing on-going support for those with chronic disease is the most cost-effective, sustainable option – especially when one considers the HHR challenges facing all health care sectors.

The home and community care sector can play an enhanced role in the prevention and management of chronic disease. For example, home care case managers could connect clients with resources in both the health and community sectors to better manage their conditions or prevent them from getting sick in the first place. Home and community care workers could act as coaches, facilitating self-managed care and helping clients take more responsibility for their health. Given that personal and home support workers are a constant factor in many clients' lives, they too could be instrumental in helping to change health behaviors. Lastly, comprehensive home and community-based chronic disease prevention and management efforts would help ease the burden on other health care sectors and providers by, for example, reducing reliance on family physicians and nurse practitioners for on-going CDPM.

"The frontline of health care is the home. Most health care starts with people looking after themselves and their families at home."

Department of Health. (2007). *The NHS Plan: A plan for investment, a plan for reform*. London, England: Author.

RECOMMENDATIONS

To help prevent illness and better manage chronic disease, VON Canada recommends that governments partner with stakeholders to:

- 1. Accelerate the implementation of comprehensive chronic disease prevention and management strategies, while maximizing the potential contributions of all sectors. Governments must provide sufficient funding and resources, as well as corresponding monitoring tools to evaluate outcomes.**

At a minimum, the following steps should be taken:

- Provide incentives to employers to proactively support the health of their employees through healthy work policies.
- Work with educators to ensure school curricula (starting at pre-school) emphasize the importance of a healthy lifestyle and highlight the consequences of chronic disease.
- Revise curricula for all health care workers to include training on chronic disease prevention and management strategies, emphasizing the important role they play and the skills they require to support people to better manage their own health and long-term conditions.
- Develop a national communications strategy to educate the public on physical and mental health and chronic disease. These campaigns should be on-going, with clear and consistent messaging tailored at a variety of audiences.
- Fund targeted programs to work with “at-risk” populations and communities to prevent and better manage chronic disease. For example, proactively identify seniors living alone who may require care and supports.
- Promote the use of client-centred models of care that acknowledge the diverse range of resources available in communities to promote health and manage chronic disease.

2. Enhance the role of the home and community care sector in the prevention and management of chronic disease. Examples of strategies to increase the sector’s capacity include the following:

- Adapt all CDPM resources and services for use in the home. For example, provide self-management support to clients in their home through in-home coaching enabled by technology that links clients to off-site health care providers.
- Provide clients and caregivers the option to choose the services that best address their needs. For example, provide clients with personal budgets or vouchers so they can “purchase” the care and services they want.
- Work with public health and primary health care to provide tailored health promotion programs and

activities to people in their homes and communities.

- Implement flexible community funding models that support “non-traditional” in-home service delivery. For example, funding to support the use of technology as a venue for monitoring client’s conditions as opposed to traditional face-to-face nursing visits.



5. CAREGIVING

Much of the care and services provided to Canadians in their homes and communities is delivered by unpaid family and friends. There are an estimated 2.85 million Canadians caring for a family member with long-term health problems.⁴¹ Family caregivers provide the majority of care needed by individuals with on-going care needs and contribute more than \$5 billion of unpaid labour annually to the health care system.⁴² Without the unpaid labour provided by caregivers, the Canadian health system would be unable to cope with increasing demands for care.

Although caregivers range in age, most are between the ages of 45-65, which are peak earning years for many. Some studies suggest that as many as one in five adult Canadians, mostly women who also work outside the home, provide unpaid care.⁴³ While caregivers acknowledge the rewards of caregiving, they often provide care at their own physical, emotional, and financial expense. For example, 50% of unpaid family caregivers report health problems, 79% report some emotional difficulty such as increased stress and sleep disturbances, and 25% report that their employment situation has been affected as a direct result of their caregiving responsibilities – ultimately interfering with pension plan contributions and possibly affecting savings for the future.⁴⁴

Similar to its treatment of home care in general, Canada’s approach to caregiving is largely *ad hoc*. Although supports and resources for caregivers are available in all jurisdictions (often through community organizations), there is no overarching national framework.

The federal government offers tax relief options to caregivers to help offset costs associated with caregiving, but many caregivers cannot afford the upfront expenses related to paying for additional services. However, some progress is being made across the country. Nova Scotia, for example, is actively developing a caregiving plan as



BY THE NUMBERS: THE COMPASSIONATE CARE BENEFITS (CCB) PROGRAM
Recent statistics show that only 51% of Canadians are aware of the CCB program, in comparison to 55% of Canadians in 2004.

HRSDC. (2008). *EI Tracking Survey 2008 – Compassionate Care Benefits*. Ottawa, ON: Government of Canada.

to be done across the country to help caregivers offset the cost of the care they provide while maintaining their own health and well-being.

Research suggests that caregivers do not feel sufficiently recognized by either the formal care system or the general public. In addition, they do not feel recognized as partners in care, or as clients in their own right needing support and relief. In addition to personal supports, caregivers require education, training and access to reliable health information to help them care for their loved ones, many of whom are living at home with complex needs.

With an aging population, fewer beds and facilities, a shortage of health human resources, and more people wanting to be cared for in their own homes, the demands on caregivers will continue to increase. Unfortunately, the number of caregivers is decreasing due to changes in

part of its continuing care strategy. And in 2004, the federal government introduced the Compassionate Care Benefit (CCB), an employment insurance benefit directed to employed people who require a leave of absence from work to look after a dying child, parent or spouse. But much remains

family structure, such as increased mobility of the population (i.e., adult children often do not live in close proximity to their parents), lower birth rates, and greater participation of women in the workforce.⁴⁵ These trends are expected to continue into the future and will likely reduce the number of caregivers available to support and care for their loved ones.

RECOMMENDATIONS

To recognize caregivers as part of the health care team and to ensure that their caregiving role should not result in undue physical, mental, or financial hardship, VON Canada recommends that all levels of government partner with stakeholders to:

1. Provide targeted resources to the health, social and voluntary sectors to help them comprehensively respond to the needs of caregivers as partners in care. Specifically, resources for caregivers should include access to:

- A personal assessment in partnership with providers to determine their health and social needs
- Support and respite services tailored to meet the needs and realities of the individual caregivers
- Education, training and information

2. Convene an expert panel on the financial security of caregivers to examine options to support caregivers

through policy mechanisms, such as:

- A Canada Pension Plan drop-out clause
- Registered Caregiver Savings Plan
- Compassionate Care Benefits
- Tax credits
- Labour code standards

3. Work with stakeholders to create an awareness campaign that recognizes the contribution and needs of caregivers. Specific messaging should be tailored to the general public, policy makers, health and social workers, and educators to influence policies, practices, and attitudes.



6. INVESTING IN HOME AND COMMUNITY CARE

Governments around the world are working diligently to reform their health and social care systems to better meet the needs of their

citizens. Increasingly, governments are turning to the home and community care sector as a focal point for change. Although Canada is one of only eight OECD countries that spend 10% or more of their GDP on health care,⁴⁶ our commitment to the home and community care sector ranks poorly internationally. In 2005, the OECD published a report looking at the long-term care systems of 19 OECD countries. On average select countries spent 0.35% of their GDP on home care. Public spending for home care was highest in Sweden and Norway (0.78% and 0.66% of GDP). Canada spent approximately 0.17%, near the bottom of the list with Spain, New Zealand and the United States.⁴⁷ This means that Sweden spends almost five times more of its GDP on home care than Canada, while Norway spends close to four times more. Although these two Scandinavian countries have a higher proportion of people over 80 than Canada, the difference is not enough to account for such a striking difference in home care spending.

Home care spending varies considerably within Canada as well, as each province and territory has designed a system based on available resources and priorities. Although not without its drawbacks^v, one way to illustrate the differences in home care systems across the country is to look at expenditures. For example, in 2005-06 total expenditures on home care varied from

1.56% to 6.8% of provinces' and territories' total health care budget. Estimated per capita public expenditures for 2005-06 varied considerably among jurisdictions – from \$82 to \$198.⁴⁸ As a result, there are varying levels of benefits and coverage available to Canadians across the country and even within jurisdictions. Who you are (i.e., eligibility), where you live (i.e., availability of services in your area) and what you can afford (i.e., terms and conditions of care and services) define what supports you will receive rather than what supports you require to remain healthy and safe in your home.

Clearly, there is much room for improvement in Canada both in terms of catching up with the global leaders in home care investment and ensuring that Canadians have access to appropriate care wherever they live across the country. If governments in Canada are serious about helping Canadians “age at home”, significant new investment in the home and community care sector is required. The number of Canadians who need – and provide – home and community care is growing every day, and it is our collective responsibility to ensure that the proper supports and systems are in place. The health and quality of life of Canadians depends on it.

RECOMMENDATIONS

To ensure that all Canadians have access to comprehensive home and community care supports, VON Canada recommends that federal, provincial and territorial governments:

1. Establish a federal, provincial, territorial (F/P/T) working group to develop and implement a comprehensive, national approach to home and community care. This universal program should be governed by principles enshrined in legislation to ensure all Canadians have equal access regardless of their circumstances.

- **As a first step, the working group should consult with health, social and voluntary sectors, educators, regulators and professional bodies to formally assess the challenges and opportunities facing the system.**

2. Increase public investment in home and community care. As a starting point, Canada should double the proportion of GDP devoted to the sector immediately, to bring Canadian investment in home and community care up to the OECD average of 0.35%.

^v As there is no consistent definition of home care services in Canada direct comparisons of home care data should not be made. However, the range of expenditures illustrates the different approaches to home care across the country.

Conclusion: Why Investing in Home and Community Care is Good Policy

The Honourable Tommy Douglas envisioned the implementation of Medicare as occurring in two phases. The first phase dealt with the public financing of the medical system and the second phase was to deal with revamping and reorganizing the delivery system beyond acute care.⁴⁹ While the first part of this vision has been implemented, decades later the second part remains to be completed.

Despite its exclusion from the *Canada Health Act*, research and experience tells us that home and community care plays an essential role in maintaining and enhancing the health of Canadians. Given the growing demand for home and community care across Canada, the sector will be increasingly relied upon to help citizens remain independent and healthy in their homes. It is incumbent on governments, as well as home and community care organizations, to work together to design and implement a model that responds to the social and economic realities of today's world to maximize the contributions of the home and community care sector for the health and well-being of Canadians.

What is currently in place, by its *ad hoc* nature, could not be called a "system". It does not meet the needs of Canadians today, and demographic and other trends suggest that it will fall far short of meeting future needs. It is therefore vital that governments take immediate steps to enhance the home and community care sector and build its capacity to provide care and services across the country. This is not something that can happen overnight. The response must include short, medium and long-term goals. It will entail tremendous change, courage and collaboration but it will pay enormous dividends. Enabling people to live, heal, and age in their

homes is a wise financial investment for governments, and a wise investment in the long-term health of Canadians.

Although the challenges facing the home and community care sector are significant, they are not insurmountable. Through the leadership of governments, and in partnership with health and social service sectors, Canadians and their communities, the vision proposed by VON Canada for home and community care in Canada can be transformed from words into action. The time has come for a home and community care system that is comprehensive and responsive to the needs of all Canadians and enables all people to give the best of themselves to their families, communities and country.



Appendix A: Glossary



Alternate Level of Care (ALC) Patient: Someone who has finished the acute care phase of his/her treatment but remains in the acute care bed. (Canadian Institute for Health Information)

Canada Health Act (CHA): Canada's federal legislation for publicly funded health care insurance. The aim of the Act is to ensure that all eligible residents of Canada have reasonable access to medically necessary services free of charge. The CHA defines the national principles that govern the Canadian health insurance system, namely, public administration, comprehensiveness, universality, portability and accessibility. (Health Canada)

Community Support Services (CSS): Community support services encompass a range of services aimed at helping people who need assistance with activities of daily living (e.g., eating, bathing, personal hygiene) and instrumental activities of daily living (e.g., vacuuming, laundry, transportation) in order to live as independently as possible in their homes and communities. Seniors, people with disabilities and medically-fragile children and their families are the primary users of CSS. (Adapted from work published by the Canadian Research Network for Care in the Community).

Home and Community Care: There are a number of definitions for home and community care, all of which are grounded in a holistic approach to health and well-being. For the purposes of this paper we have adopted the definition cited in the *Report to the Annual Premiers' Conference* (2002):

Home and community care is the provision of health care, community and social support programs that enable individuals to receive care at home and/or live as independently as possibly in the community.

Home Support Services: The provision of personal care, homemaking services and/or respite to enable the

individual to remain at home in a safe and acceptable environment. (Canadian Home Care Association)

Medically Necessary: Under the Canada Health Act, the provincial and territorial governments are required to provide medically necessary *hospital* and *physician* services to their residents on a prepaid basis, and on uniform terms and conditions (Health Canada). Home and community care are not considered "medically necessary" under the CHA. Therefore, provinces and territories are under no obligation to fund or provide home and community care services.

Personal Care/Supports: Assistance with activities of daily living which may include help with dressing, bathing, grooming, feeding, toileting, mobilization and transferring. (Canadian Home Care Association)

Social Determinants of Health: The economic and social conditions that influence the health of individuals. According to the Public Health Agency of Canada, the social determinants of health include income and social status, employment/working conditions, gender, health services, social support networks, social environments, healthy child development, personal health practices and coping skills, education and literacy, physical environment, culture, and biology and genetic endowment.

Social Capital: There are a number of definitions for social capital, but in essence social capital refers to social connection. For the purposes of this paper we have adopted the following definition:

The norms and social relations embedded in the social structures of societies that enable people to co-ordinate action to achieve desired goals.
(Organisation for Economic Co-operation and Development)

Appendix B: Recommendations from the Canadian Home Care Association's ICT Report

VON Canada endorses the recommendations outlined in the Canadian Home Care Association report, *Integration through Information Communication Technology for Home Care in Canada* (March 2008). The recommendations from the report are as follows:

First and foremost, fundamental to the advancement of ICT in home care is a paradigm shift by policy makers and funders away from episodic, acute care to a focus on the health care outside of the hospital where individuals experience the majority of their health care.

- Invest, as a priority, in technology solutions that support identified linkages between primary health care teams and home care to enable improved integration, communication and collaboration.



- Invest in the implementation of an electronic clinical information system for home care that includes all elements of service delivery and is available at the point of care, wherever that service is provided.
- Host an interdisciplinary roundtable to determine the key information / data elements of an integrated electronic health record that includes information that is “pushed” and “pulled” from home care.
- Support demonstration projects that enable the introduction of consumer based technologies (e.g., point of care tools) that empower the consumer, improve access and sharing of health information with the health team.
- Support home care programs/providers to implement technology applications for administrative processes (to support monitoring, evaluation and planning of home care services) as a basic minimum requirement.
- Establish linkages between the electronic clinical information system for home care and the broader health care system, e.g., acute care, long term care, primary care.
- Leverage ICT applications (e.g., telehealth in all its forms) as a key strategy for managing risk for individuals remaining at home as they age.
- Provide forums to champion and leverage local ICT successes and broadly disseminate strategies to advance adoption in other communities.
- Support research into the outcomes and effectiveness of new technology applications for home and community care and its impacts on health human resource utilization and client empowerment.

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