



Living Up to the Promise

Addressing the high cost of underfunding and fragmentation in BC's home support system

SUMMARY REPORT

By Marcy Cohen & Joanne Franko

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The Importance of Home Support for an Aging Population

HOW DO WE as a society address the health challenges of an aging population? What kind of services and supports are needed for seniors to maintain their independence, remain socially engaged and still be supported as their health declines? Given growing concerns about the rising health costs of an aging population, finding solutions – that maximize both cost effectiveness and health outcomes – is one of the biggest challenges facing BC’s health care system today.

The Ministry of Health’s stated goal is clear enough: support seniors to remain independent in their own homes for as long as possible.¹ The reality on the ground is, however, something different. Instead of making it easier for seniors and family caregivers to access the basic home support services seniors need to remain in their own home – such as assistance with meal preparation, bathing, and medication management – it is now more difficult than ever for older adults, particularly those with more moderate needs, to access these services.²

From 2001/02 to 2009/10 access to home support services for people 75 and over declined by 30 percent.³ In 2013-14 the number of clients receiving home support was virtually identical to the number receiving services in 2001-02. Yet, over those 12 intervening years in BC, there was a 49 percent increase in those clients 80 years or older,⁴ and an increased demand for home support services due to shorter hospital stays and more restricted access to residential care.⁵

BC was a leader in the provision of prevention-oriented home support services from the 1960s to the mid-1990s.⁶ This is no longer the case. Today, BC’s Ministry of Health has the most restricted criteria for accessing basic homemaking services, like meal preparation and laundry, of any Canadian province.⁷ If you look more broadly at the full range of publicly funded home health services (i.e. inclusive of home making, personal care and professional nursing and rehabilitation services), less than two percent of BC’s population has access to these services – also lower than any other province in the country.⁸

In this research project, focus groups were organized with the people most directly connected to the home support system – the

clients, family caregivers, family physicians, home care nurses and community health workers (i.e. home support workers) – in order to learn about their experiences with the shortfalls in the home support system, and to reflect on how these experiences compare with what the research tells us is needed to provide high quality, cost effective care and support for seniors as they age. There were 44 focus group participants, primarily from two health authorities – Vancouver Coastal Health and Fraser Health.

This research project builds on a number of earlier studies on the BC home support system and on reports from both BC's Auditor General and Ombudsperson. These reports were critical of the lack of leadership provided by BC's Ministry of Health to ensure that home support services are adequate to meet population needs.^{9 10} The overall goal of this report is to develop recommendations for the Ministry of Health on the key changes needed to improve the home support system in ways that will optimize the quality of care and the overall cost effectiveness of health services.

The full report (www.icadvocacy.ca) includes the findings from the focus group research and a review of the research literature on the way home-based services can be organized to: support healthy aging, address the burden of care on families, and ensure high quality, cost effective service delivery. The shorter report below summarizes the key findings from the focus groups and insights from the research literature.

What We Learned from the Focus Group Participants

Home support services more task-oriented, less person-and family-centred

DUE TO THE growing demand for services and limited resources, the role of the community health worker has become narrower and more task-oriented. Community health workers are now required to follow rigid protocols that make it more difficult for them to respond flexibly to their clients' needs and establish trusting and meaningful relationships. As a result, person- and family-centred care and care continuity – so critical to health related quality outcomes – has been severely compromised.

Below are some reflections on these changes from a community health worker, a family physician and the friend of someone with Alzheimer's:

“If something isn't in the care plan, I can't do it, no matter how simple it is. I can't chat or socialize with clients at all, take out the garbage, make toast or a snack. Clients ask me to do little things, and they get frustrated when I can't do it – they are not in charge of the services...”

(Community Health Worker)

“Really what most people need is some more flexibility about how a community health worker uses the time. The bigger question is: ‘What does a person really need in order to be able to stay in their own home?’ It goes beyond help with medications and personal care.”

(Family Physician)

“One of my friends has Alzheimer's and the home support was just meaningless because...while they do try to send the same person, she just has 20 minutes or something and she runs in ... I've been there when she runs in, and checks that there's something easily visible in the fridge for dinner and she makes sure that my friend takes her evening medication at 4:30. Very task-oriented! No relationship...”

(Family friend)



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(Community Health Worker)

When you don't have access to a care plan, you can't actually know what is wrong with the person and then you aren't using your skills...it really limits your ability to provide person-centered care because you are just focussed on the task...not actually thinking about the person.

(Community health worker)

Because of how privacy laws are being interpreted and applied in many settings, community health workers reported they only have access to information on the client's care plan related to the specific tasks they are expected perform but not the client's overall health history and diagnosis. A community health worker's access to information about their client's condition is critical if they are to provide quality care to their clients:

"When you don't have access to a care plan, you can't actually know what is wrong with the person and then you aren't using your skills...it really limits your ability to provide person-centered care because you are just focussed on the task...not actually thinking about the person."

(Community health worker)

Social support no longer part of community health worker's role

THERE ARE MANY studies showing the positive health benefits when seniors have meaningful social connections and social support. Social support slows cognitive decline, the onset of dementia, and the progression of physical disability.¹¹ In contrast, feeling isolated from others can "disrupt sleep, raise blood pressure, lower immunity, increase depression, lower overall subjective wellbeing and increase the stress hormone cortisol."¹² Preventing isolation is critical to healthy aging. As one registered nurse pointed out:

"Social isolation is thought to be a big reason that older, community living people...come into emergency. They come in simply because they are lonely. Since there is no other obvious diagnosis, the chart will often say: 'Failure to Thrive.'"

(Registered nurse)

Yet social support is no longer part of the community health worker's role.

"We had an example of a client who wasn't in the mood for the regular services that the community health worker provides. She didn't want help with bathing and dressing and she said she just wanted to die...and the community health worker wasn't in a position to just sit down and hold the client's hand when she knew this was what was needed most."

(Registered nurse)

In fact, community health workers are not even able to help their clients and/or family caregivers access information about the social support services available in their local community.

“Home support workers are actually discouraged from sharing information about community services like Meals On Wheels, adult day services and Handy DART services...that kind of thing...we know these are tasks that aren’t included on the care plan and we could be reprimanded for this.”

(Community health worker)

Lack of continuity challenging for clients and family care givers

IT IS BROADLY acknowledged that continuity (having the same worker or team of workers) is important to good quality outcomes for the person receiving care.¹³ But shorter visits and scheduling challenges make this very difficult to achieve. For family caregivers, the revolving workforce is very challenging:

“Respite is really important for family caregivers and when you have been able to build rapport with a home support worker you feel more comfortable leaving the home.”

(Family caregiver)

Along a similar vein, one of the nurses noted:

“Quite often clients are refusing home support services because it is a different person every time and they don’t have the time or energy to ‘retrain’ different community health workers.”

(Registered nurse)

The health authorities are aware of this problem and have developed new positive models, like cluster care, to address the need for more continuity. However, cluster care only works in areas where there is a high concentration of seniors and even in those locations the pressure of rising caseloads can make it challenging for workers to respond flexibly to client needs.

Lack of support for family caregivers problematic

ALMOST ALL OF the seniors receiving publicly funded home health services also have an informal (i.e. unpaid) caregiver, most often a family member.¹⁴ These family caregivers play a crucial role in supporting frail seniors to remain in

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(Registered nurse)

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(Registered nurse)

their own homes, and yet increasingly they experience difficulties in accessing the respite and social support they require.¹⁵ These problems seem particularly acute for caregivers whose spouse or parent is living with dementia:

“Years ago, St. Paul’s had an excellent team to assess and help with my husband’s dementia. I was able to count on support from the Burnaby Health Department and had good contact with the home support workers who were all very skilled at their job... Things are quite different now... We ended up foregoing public services because it was no longer helpful to us.”

(Family caregiver)

“My Dad only wanted my Mom to help even though sometimes she wasn’t able to, and I was powerless to encourage the home support worker to persist. The agency’s response was: ‘There is really nothing we can do if the client is refusing help.’ Dad was diagnosed with early on-set dementia and had challenges with personal care, always wearing a diaper and not wanting to be cleaned. So he was forced to go into residential care. He was only there a short time when he got pneumonia and then was asked if he wanted to go back home!”

(Family caregiver)

More than a quarter of family caregivers report being ‘sandwiched’ between caregiving for children and aging parents¹⁶ which means that having access to a more flexible and responsive home-based care is an important issue not only for seniors, but also for younger families and employers.

Shortage of case managers undermines access, communications and trust

ALL OF THE focus groups talked about the pivotal role of the case manager as a ‘point of entry’ for accessing and coordinating services, and noted that the shortage of case managers is creating critical bottlenecks in the system:

“Getting past Central Intake for Home and Community Care in Vancouver Coastal and Fraser Health is getting harder and harder. The bar is obviously rising on who can get a case manager to visit and assess needs...In addition, case managers are supposed to check with their on-going cli-

ents once a year, but due to very heavy caseloads they may only check in every two years....”

(Gerontologist & Co-ordinator for family caregiver education and support programs)

Participants in the nurses and community health worker focus groups talked about the increasing challenges community health workers experience when trying to get a case manager to respond to their concerns. In the past they could connect directly with a case manager but this is no longer allowed:

“You can’t contact a case manager directly to report a problem...We have no choice but to rely on the supervisor to report issues to the case manager but they also have challenges getting through to a clinician to get an increase in care....”

(Community health worker)

From the discussion in the focus groups with community health workers and family caregivers it was clear that the lack of communication with the case manager was eroding their trust in the system. As one family caregiver noted:

“I am so disappointed from the lack of support from the government. I never even met our caseworker face-to-face. The first and only phone call from the original caseworker came on a Friday evening at 9:00pm. I left seven different messages for a new caseworker and have not received a call back.”

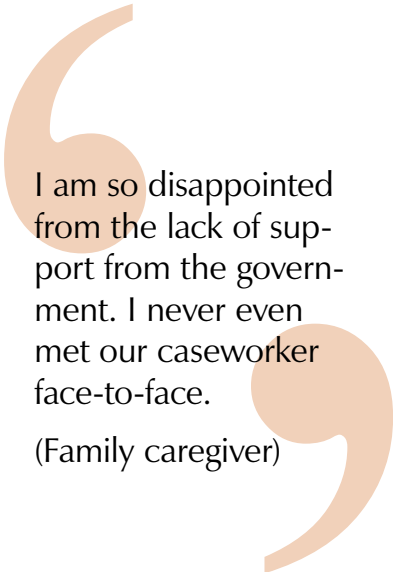
(Family caregiver)

The community health workers, in turn, talked about how their input was not welcomed or valued by either their supervisor or the case manager:

“Workers are often seen as ‘over-stepping’ professional boundaries and reports and observations tend to be ignored or discounted.”

(Community health worker)

Yet in the research and professional practice literature, proactive communications and teamwork are widely recognized as essential in preventing health crises and avoiding unnecessary hospitalizations ^{17 18} (see section below).



I am so disappointed from the lack of support from the government. I never even met our caseworker face-to-face.

(Family caregiver)

A greater focus on early intervention and preventative care needed

We need the community health workers and the system needs to support them in their early intervention efforts...putting out little fires and alerting the case managers or primary care physician.

(Family physician)

IN BC TODAY it is very difficult for seniors with low to moderate needs to access home support services and yet there is substantial evidence on the health benefits and cost savings of early interventions and preventative care.^{19 20} The physicians and registered nurses in the focus groups strongly support early interventions and the role community health workers play in helping to monitor changes in the client's health status, and averting health crises:

"We need the community health workers and the system needs to support them in their early intervention efforts... putting out little fires and alerting the case managers or primary care physician."

(Family physician)

"...Services like meal preparation and housework, 'checking in' and emotional support...can be integral to frail seniors living at home, especially when family is not available to pick up the needs."

(Registered nurse)

For people with dementia, the lack of support for early interventions can be particularly challenging. As one of the community health workers noted:

"I have visited clients who are just new to the service but, unfortunately, their dementia has progressed to the point where they become agitated and afraid of me because I am a stranger to them. The health authority needs to give some of these moderate needs people with dementia some minimum level of services earlier on...so it won't be quite so traumatic when it comes time to help with things like personal care. These people may not be able to remember your name but they are more comfortable because of some familiarity."

(Community health worker)

There is also very compelling evidence in the research literature showing that appropriately delivered early interventions – including regular monitoring by a case manager – can extend the time that a person living with dementia can remain in their own home.²¹

Home support ill-equipped to deal with increasingly frail and complex clients

MANY OF THE focus group participants commented on the fact that the home support system was ill-equipped to deal with the increasingly frail and medically complex clients on their case loads. The community health workers were particularly concerned about the lack of adequate training to support them to work with higher needs clients:

“Nowadays, there are a lot of complex care clients needing tracheotomy care, and there are not many community health care workers who have been trained to do this procedure properly. This is not even covered as part of our HCA training courses; we have to pay out of pocket for the specialized training.”

(Community health worker)

The participants at the nurses’ focus group noted that community health workers increasingly get requests to perform tasks that are traditionally nursing duties. However because of growing workloads in home care, registered nurses are less able to provide the coaching and support community health workers require to successfully take on these added responsibilities. The nurses felt that employing more licensed practical nurses (LPNs) could address some of the gaps in the current home support system. An LPN who was part of the focus group had this to say:

“I have to wonder why more LPNs aren’t employed to provide the necessary care. There are many LPNs, who are currently trained, but underemployed. Other provinces like Ontario use many more LPNs in the community than BC does...”

(Licensed practical nurse)

Multi-disciplinary team-based care an important part of the solution

RESearch shows that access to a multidisciplinary team is the best way to improve quality of care and cost effectiveness when caring for a frail senior with complex needs.²²

²³ Palliative care is one area where multidisciplinary teams of community health workers and nurses can make a positive difference. One of the physicians noted that with better access to

team-based services, more palliative care clients would be able to receive care at home rather than in-hospital:

“The home and community care team needs to be there to support that person in the last stage, in the last few days... if that happened, there would be more physicians willing to take on that type of care...knowing the patient was going to have support from a team.”

(Family Physician)

Multi-disciplinary teams in other jurisdictions have been very effective in supporting older, frail seniors after an acute illness or hospitalization when they are at particularly high-risk for functional decline. This type of intervention is referred to as restorative care. Instead of simply having the home support worker do specific tasks for the individual, the older adult is supported by a multi-disciplinary team to redevelop the skills and confidence needed to do things for themselves and to build connections with new networks of social support. Research from Australia shows that restorative care programs are effective at reducing the use of emergency and hospital services, and lowering overall health-care costs.²⁴

A community health worker in the focus group pointed out that while there is an acknowledgement of the benefits of a restorative approach to care, it is not the reality on the ground:

“If my client is having a slow day, I don’t have time to get her to do things herself. I’m supposed to encourage her to do things herself, but that takes too much time. I realize this means she is losing capacity by having everything done for her...”

(Community health worker)

A System at the Breaking Point: Future Directions and Recommendations

“It is not just a question of more resources, although that is clearly needed. It’s also a question of how we distribute those resources and use them. We need courageous leaders!”

(Family Physician)

OVERALL, A REMARKABLY strong consensus emerged from the focus group findings: that is, the home support system could be doing so much more to help seniors to maintain their health and live independently if there was more emphasis on social support, early interventions, restorative care and team work. These findings correspond with what the research literature tells us is needed to provide high quality, cost effective care to seniors as they age.

It was also clear from the focus group discussions that home support agencies and/or health authorities have not been able to resolve the challenges in home support on their own. Leadership from the provincial government is urgently needed. This was certainly the overriding message from the Auditor General in his 2008 report where he concluded that the Ministry of Health was not “adequately fulfilling its stewardship role in helping to ensure that the home and community care system has the capacity to meet the needs of the population.”²⁵

Similar concerns raised by the Ombudsperson in her 2012 report focused on the lack of oversight and support from the Ministry of Health in ensuring that their own goal – to support seniors to remain at home for as long as possible – could be realized.²⁶ The failure of the Ministry of Health to act on the recommendations from the Auditor General and Ombudsperson have brought the system to a breaking point.

We would, therefore, make the following two recommendations that the Ministry of Health:

- 1. Provide the funding for home support that is required to increase staffing levels, teamwork and training, and to increase the number of case managers, community rehabilitation staff, registered nurses and licensed***

practical nurses available to support community health workers in providing care to older adults at home with chronic, acute and palliative care needs. The funding should be based on a plan that includes significant targeted yearly increases over the next ten years tied to the system improvements outlined in the second recommendation below.

- 2. Develop a plan for how to align BC's home support delivery system with current research on what is needed to provide high quality, cost effective services that are inclusive of family caregivers, support seniors to better manage their chronic physical and mental health challenges, and ensure that seniors can remain as independent and socially engaged as possible.***

The plan would include the following key elements:

- An advisory committee to guide the change process with representation from: family caregiver groups, seniors' organizations, community agencies providing social supports to seniors, health policy experts, and front line providers (i.e. nurses, family doctors, community health workers).
- A priority focus on early interventions and prevention to ensure that seniors' need for social support, good nutrition, exercise and other basic services are addressed by both the home support system and through better co-ordination and linkages with community agencies providing social support services to seniors.
- A restorative team-based model of care for seniors following an acute illness and/or hospitalization to restore independence and reduce functional decline, and training for community health workers to ensure they play a lead role in providing this care.
- A process for ensuring that all community health workers have access to information on their clients' medical history and diagnosis prior to their first visit, that this information is regularly updated and available to the family physicians as well as the home and community care staff supporting the client.
- Systemic recognition of the role of community health worker in preventing health crises including the expectation that

their input will be acknowledged and appropriately addressed, and a protocol developed to inform the family physician/ nurse practitioner in case of a crisis or acute medical issue.

- New opportunities and training for community health workers to work in teams with case managers, nurses and/or family physicians in caring for clients with advancing dementia, severe and/or multiple chronic ailments and/or in need of palliative care.
- Inclusion of the family caregivers as full members of the care team with access to respite care, social support and education as needed.

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