



# Living Up to the Promise

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

By Marcy Cohen & Joanne Franko

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# 1. The Importance of Home Care Supports for the Aging Population

**F**INDING EFFECTIVE WAYS to support and care for people as they age is an increasingly important issue. Over the next 15 years the senior population in Canada will grow rapidly as the large baby boom generation reaches 65 years of age. By the year 2036, close to one quarter of all Canadians will be 65 and over, compared to just over 15 percent in 2013.<sup>1</sup> By 2045, when the youngest in the baby boom generation reaches 80, close to 40 percent of the seniors population will be 80 years or older.<sup>2</sup>

Concerns about the rising costs of an aging population frame much of the discussion in the media about the future sustainability of our public health services. Yet a recent report from the Canadian Institute for Health Information found that “the proportion of health spending dedicated to seniors actually held nearly steady at around 45 percent between 2002 and 2012, even as the percentage of seniors in the population grew from 12.5 percent to 14.9 percent.”<sup>3</sup> In fact, overall population growth and inflation had a stronger impact on health spending than the aging of the population.<sup>4</sup>

At the same time, there is a growing concern among seniors – and younger people with aging parents and grandparents – about the adequacy and effectiveness of the current system of seniors’ care and support services. Today, more seniors are living longer, healthier lives than at any time in the past, and many older adults are able to retain their independence and social connections well into their 80s. Still, as people age and begin to experience cognitive and physical challenges they require more support and assistance to remain in their own homes and stay socially engaged. For seniors in the oldest age categories, where the prevalence of dementia and other chronic conditions is the greatest, the home is increasingly becoming a setting for long-term care, with family and friends assuming the majority of the care-giving burden.

Seniors and their families have a strong preference for services that support older adults to live in their own homes as long as it is practical and in the best interests of all family members. There is also a growing consensus that ‘aging in place’ is the most cost effective and appropriate way of supporting the needs of our ag-

ing population.<sup>5</sup> This perspective is shared by the BC Ministry of Health, whose long term stated policy goal has been to support seniors to remain independent in their own homes for as long as possible. One of the key goals the Ministry of Health's redesign of home and community care, announced in 2002, was to avoid the unnecessary institutionalization of seniors by expanding home support and creating an assisted living program.<sup>6</sup> The policy objective of supporting seniors at home was restated in the Ministries' strategic policy framework on primary and community care released earlier this year.<sup>7</sup> However, the Ombudsperson – in her four year systemic investigation of seniors care services in BC – raised concerns that the reality on the ground may be very different than the policy statements because of the “limitations on home support services.”<sup>8</sup>

The intent of this report is to examine whether the basic services offered through the publicly funded home support system (see description in the glossary of terms on page 4) are currently meeting the needs of the senior population, and how these services could be organized and delivered in future to better support seniors to remain at home for as long as possible. To this end, focus groups were conducted with health providers, seniors and informal caregivers who have direct experience with BC's home support system. In analyzing the focus group findings, we were interested in understanding not only how effective home support services are, but also how these services could be integrated with other community health and social support services (e.g. home care, palliative care, physician services and community-based seniors' services) to ensure a higher quality, more cost effective system of care and support for people as they age.

To set the context for this analysis, the report begins by looking at what the research literature says about how home-based services should be delivered and organized to: support healthy aging, address the burden of care on families, and ensure high quality, cost effective care.

## Glossary of Terms

**HOME SUPPORT:** Home support services are direct care services provided by community health workers (CHWs) to clients who require personal assistance with activities of daily living, such as eating/feeding, personal care (e.g. bathing, dressing), basic nursing tasks, and assistance with mobility lifts and transfers.

Community health workers may perform some other specific nursing and rehabilitation tasks that have been delegated by a health professional (e.g. medication administration, simple wound or bowel care, rehabilitation activities). Home support services can also be respite care, providing caregivers with temporary relief from the demands of providing care.

In the past, home support included assistance with meal preparation, laundry and light housekeeping. These services are no longer included except in circumstances deemed “necessary to client safety.”

**COMMUNITY HEALTH WORKERS:** Until the 1990s community health workers were referred to as ‘homemakers’ and there were no formal job requirements. Today the basic requirement for eligibility to work as a community health worker is the successful completion of the Health Care Assistant Program (HCA Program) at a recognized educational institution. These six-month programs prepare students to work with a wide range of clients in a variety of health care settings. The HCA Program is currently being reviewed and enhanced to reflect the increased complexity of the clients receiving home support services.

According to current information from the Health Employers Association of BC (HEABC):

- The average age of a community health worker in BC is 46.3 years;
- Approximately one third of community health workers are 55 years or older (a 3% increase from 2009);
- The average annual salary for a full-time community health worker is approximately \$37,530 or \$19 an hour.

**HOME CARE:** Services provided by the health authorities who employ professional nurses to deliver services (including post-acute, chronic and palliative care) to individuals in their own homes.

**COMMUNITY REHABILITATION:** Services provided by the health authorities who employ licensed physiotherapists and occupational therapists to deliver rehabilitation services to individuals in their own homes

**HOME HEALTH SERVICES:** All professional and non-professional health services provided to individuals in their own homes. Includes home support, home care and community rehabilitation services.

## 2. A Review of the Research Literature

### What Makes a Difference to Healthy Aging?

**T**HE WORLD HEALTH Organization and the Public Health Agency of Canada recognize social support as a key determinant of health. When seniors have meaningful social connections, they “develop their resilience and ability to bounce back after adversity, as well as an ability to gain strength from stress rather than be diminished by it.” 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.”<sup>9</sup> In addition to experiencing poorer emotional and physical health, socially isolated seniors are also at a higher risk of over-consumption of alcohol, falling, and suffering from poor nutrition.<sup>10</sup> The risks of social isolation are highest among poor and visible minority senior populations.<sup>11</sup>

Researchers recently quantified what they refer to as the effects of the ‘loneliness disease’, warning that lonely people are nearly twice as likely to die prematurely compared to those who do not suffer feelings of isolation.<sup>12</sup> In a similar vein, a 2011 report from Vancouver Coastal Health’s SMART Fund highlights the key findings from a number of studies on the health benefits of social support for an aging population. In these studies social support proved effective in slowing cognitive decline, the onset of dementia, and the progression of physical disability.<sup>13</sup>

As people age they are increasingly likely to suffer from one or more chronic conditions; their mobility often becomes more restricted and personal support networks begin to shrink. For these reasons, preventing isolation in this population may require intervention by a medical/nursing professional, home support and/or a community agency. Recent longitudinal research with older adults in the UK shows that older adults can, in effect, “‘recover’ from loneliness with all the potential health, social and quality of life benefits that this can bring.” Two interventions were identified as important in facilitating this recovery: “enhanced social networks” and “improved treatment and management of chronic health problems – both mental and physical.”<sup>14</sup>

Along with social support, exercise and good nutrition are key to healthy aging. Many studies document the benefits of good nutrition in maintaining health and preventing disease, particularly for frail seniors. Well-nourished seniors have “fewer medical complications and diseases, faster wound healing, and fewer infections,” whereas malnourished seniors experience “decreased quality of life, decreased independence, deterioration in overall health status, increased use of health-care resources, and increased morbidity and mortality.”<sup>15</sup>

Mobility also promotes healthy aging and facilitates independence and longevity, yet almost half of older adults living in the community report some type of limitation in mobility.<sup>16 17</sup> Fortunately, mobility in older adults can be significantly improved with physical activity programs that include a combination of aerobic exercise and resistance training aimed at increasing balance, walking endurance and muscle strength.<sup>18 19 20 21 22</sup> Research has also shown that these programs can have broader benefits as well.<sup>23</sup> Enriched interactions between ‘a leader’ and participants can result in increased perceptions of control and enjoyment, and overall life satisfaction.<sup>24</sup>

While the home support system cannot assume the full responsibility of ensuring that seniors are socially supported, well-nourished and have access to regular exercise, these key components of healthy aging need to be incorporated into the thinking about how home support services are organized and delivered.

## **What Does Quality Care for an Aging Population Look Like?**

**A**S MENTIONED ABOVE, improved treatment and better management of chronic health problems – both mental and physical – is central to supporting seniors as they age. A review of the recent research literature shows that emergency room visits and hospitalizations for seniors with chronic health conditions can be significantly reduced if seniors receive care from a multi-disciplinary team that includes a case manager and if, in addition, they are provided with education and support to better manage their chronic health challenges.<sup>25 26</sup>

Related to this is the growing recognition – from clinicians and older adults alike – that the primary goal of health care interventions, particularly for older seniors with significant and/or mul-



tiple chronic conditions, should be to optimize the person's function and comfort rather than to treat or cure a specific disease.<sup>27</sup> This is often referred to as restorative care or re-enablement and is most often recommended after an acute illness or hospitalization when older adults are at particularly high-risk for functional decline. There are, in addition, many other situations where a restorative approach to care could be beneficial (e.g. following the death of a spouse, when the individual moves to a new setting, etc.).

A restorative care philosophy differs from regular home support in some specific ways. Instead of simply having the home support worker do specific tasks for the individual, the older adult is supported by an interdisciplinary team to be as independent as possible. The goal is to support the older adult to develop or redevelop the skills and confidence needed to do things for themselves (perhaps in new ways) and to build connections with new networks of social support.

In Australia, a restorative approach to home care has proven more effective than regular home support at improving self-rated health, confidence and well-being, and at reducing mortality and the need for residential care.<sup>28</sup> The seniors in these restorative care programs required less ongoing support and used fewer emergency and/or in-hospital services, and as a result, overall healthcare costs were lower.<sup>29</sup> Importantly, the home support workers, who were provided with additional training in care co-ordination, played a key role in making this program successful.<sup>30</sup> The benefits of this program are acknowledged by BC's Ministry of Health as a best practice and yet, as we'll see further on in the report, it is very difficult to implement restorative care practices given the current resources and fragmentation in BC's home and community care system.<sup>31</sup>

There is also international evidence of the benefits of offering home support services to people with more moderate needs: for example, people who only require assistance with things like meal preparation, laundry and housekeeping. These early interventions operate as "an early warning system" for the health system, helping to monitor changes in health status, avert health crises and delay admission to residential care.<sup>32</sup> In Denmark, research in the late 1980's showed that people often waited too long to ask for care, and when they did request support, their care needs were higher and more costly. Based on these findings,

Denmark passed a law requiring that care services be proactively offered annually to every Danish senior who is 75 and over. In contrast to Denmark that has retained home support for people with very moderate needs, Sweden has concentrated their services on people with higher care needs. Decades later, the overall eldercare costs in Denmark are considerably lower than in Sweden.<sup>33</sup>

For people living with dementia and their families, there is very compelling evidence that appropriately delivered early interventions can extend the time that a person living with dementia can remain in their own home.<sup>34</sup> To be effective, these early interventions must be multi-pronged, include psycho-educational support, active engagement and specialized training for home health services staff, and comprehensive monitoring by a case manager.<sup>35</sup> With these elements in place, it is possible to alleviate symptoms and behavioural problems in persons with dementia, and reduce the negative effects of caregiving (e.g. depression and social isolation).<sup>36</sup>

## Why Include Caregivers as Part of the Care Team?

**A**CCORDING TO A 2010 study from the Canadian Institute of Health Information, 98 percent of seniors receiving publicly funded home health services also had an informal (i.e. unpaid) caregiver, most often a family member.<sup>37</sup> Clearly, family caregivers play a crucial role in supporting frail seniors to remain in their own homes and should be viewed as part of the care team. This perspective is consistent with the literature on caregiving and in particular, with findings of a recent research study emphasizing that in home and community care settings, the older person and the informal caregiver constitute the ‘unit of care’.<sup>38</sup>

Although the role of caregiver may be satisfying for many people, and social supports can mediate negative effects, the physical and mental health consequences for the caregiver can be devastating including: anxiety, sleep disturbance, higher than usual psychotropic drug use, social isolation, depression, lower levels of well-being, and increased mortality.<sup>39 40 41</sup> According to a survey by Statistics Canada, in 2012, 44 percent of caregivers are between the ages of 45 and 64. The survey also found 28 percent of caregivers reported being ‘sandwiched’ between caregiving for children and aging parents, and many experienced financial

and employment-related challenges due to their caregiving role.<sup>42</sup> Consequently, having greater access to flexible and responsive home and community-based services is an important issue not only for seniors, but also for younger families, employers, and health policy experts.

## The Implication of the Research Evidence for this Study

**T**HIS RESEARCH POINTS to the importance of programs that support healthy aging, team-based care, early interventions and restorative care. It also provides a framework for assessing the effectiveness of BC's home support services and for defining our research question: that is, ***does BC's approach to delivering home support services reflect research literature's current thinking as to how to provide high quality, cost effective care that is inclusive of family caregivers, supports seniors to better manage their chronic physical and mental health challenges, and ensures that they can remain as independent and socially engaged as possible?***

To answer this question, it is important to look both at level of service provision (i.e., are there enough home support services to meet current needs?), and at how those services are delivered (i.e., are they organized in ways that will optimize quality and cost effectiveness?). This next section addresses the adequacy of service level question by comparing current and past service levels, and then comparing access in BC to that of other provinces (section 3 below). The second question is addressed in the key findings section (section 4) and then analyzed in the discussion and recommendations section at the end of the paper (section 5).

### 3. Are Service Levels Adequate in BC's Home Support System?

**T**HE STATED GOAL of BC's Ministry of Health is "to help individuals to remain independent in their own homes for as long as possible."<sup>43</sup> In reality, access to home support services have declined significantly in recent years. From 2001/02 to 2009/10, access to support home services for people 75 and over declined by 30 percent and services were increasingly restricted to those with higher, more complex needs.<sup>44</sup> In 2013-14 the number of clients receiving home support was virtually identical to the number receiving services in 2001-02 and yet, over those 12 intervening years in BC, there was a 40 percent increase in the number of seniors 65 and over, and a 49 percent increase in those 80+ years.<sup>45</sup>

Moreover, people are now discharged from hospital 'sicker and quicker' and access to residential care is more restricted, contributing to the increased reliance on home support services.<sup>46</sup> To cope with growing demand for limited resources, eligibility criteria for home support services are becoming increasingly restrictive and seniors with moderate needs are much less likely to be able to access publicly funded home support services.<sup>47</sup> As a result, an increasing number of seniors, particularly those with low income, end up waiting until they have a health crisis and/or are admitted to hospital before they are offered access to home support services.<sup>48</sup> A recent report from BC's Seniors Advocate confirms the fact that BC's Home and Community Care system is caring for "highly complex clients" who are living at home.<sup>49</sup>

The shortfall in BC's home support services is thoroughly documented by the provincial Ombudsperson in her four-year systemic investigation into care services for seniors. In her final report, *Best of Care: Getting it Right for Seniors*, the Ombudsperson criticizes the Ministry of Health for not providing the leadership and oversight needed to ensure that they are, in fact, meeting their stated goal of supporting seniors to stay at home for as long as possible.<sup>50</sup>

Further evidence of the shortfall in home support services is provided by analyzing access to home support services in BC as compared to other provinces. From the 1960's to the mid-1990's BC was a leader in the provision of prevention-oriented home support

services.<sup>51</sup> This is no longer the case. B.C.'s Ministry of Health has the most restricted criteria for accessing basic homemaking services like meal preparation and laundry of any province in the country.<sup>1</sup> <sup>52</sup> Yet according to a recent study by the Health Council of Canada, these were the services most often needed by seniors to continue to live at home.<sup>53</sup> A number of the other provinces include a much broader range of homemaking services as part of their publicly funded home support system.<sup>54</sup> <sup>2</sup> 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, lower than any other province in the country.<sup>3</sup> In six provinces, three percent or more of the population access home health services – over a third more than in BC.<sup>55</sup>

It is clear that service levels in home support are too low and need to be addressed. One of the main reasons for organizing the focus groups was to hear from the people most directly connected with home support system – the clients, family caregivers and health care providers – about their experiences with the shortfalls in home support services and to reflect on how these experiences compare with what the research tell us is needed to provide high quality, cost-effective care.

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1 Light housing is also no longer provided by the home support program funded through the health authorities but is available through the United Way's Better at Home Program. This program is very controversial because of its reliance on volunteers and the fact that these services are not integrated as part of the continuum of home support services provided through the health authorities.

2 Three provinces – Newfoundland and Labrador, Ontario and Quebec – offer assistance with banking, budgeting and filling out forms and finding services, and five provinces – New Brunswick, Saskatchewan, Newfoundland and Labrador, Ontario and Quebec – help clients to run errands, shop and attend appointments. None of these services are offered in BC through the provincially funded health authorities program, although the United Way Better at Home program does provide some transportation support and assistance with shopping.

3 In Newfoundland and Labrador the portion of people accessing home health services are lower than in BC but are not comparable because they do not include professional services like nursing and rehabilitation.

## 4. Key Findings from the Five Focus Groups

If something isn't in the care plan, I can't do it, no matter how simple it is. You build up a relationship and want to help – that's why we got into this work. I can't chat or socialize with clients at all, take out the garbage, make toast or a snack. If I notice they are out of milk or eggs, I can't do even just a little bit of shopping. 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)

**T**HE KEY FINDINGS summarized in this section of the report are based on focus group meetings with the following five groups: geriatric and family physicians, nurses, community health workers (see glossary of terms in Section 1, page 4), seniors that are currently receiving home support services, and, family/informal caregivers (complete list of participants in Appendix A). The focus group participants were asked to describe: a) their experiences with BC's system home support services, b) the quality of relationships and effectiveness of communication between clients, community health workers, informal caregivers, home support supervisors, case managers, physicians and home care nurses; c) what they saw as the major challenges and shortfalls in the current system, and their ideas for how to make positive changes (see focus group questions in Appendix B).

The vast majority of the responses from the focus group participants focused on the shortfalls in the current system. Their concerns have been grouped under two main headings: 1) the changing nature of the care experience for clients, family caregivers and frontline staff, and 2) the focus group participants' perspective on the need for systemic change. While there were only 44 participants in the focus groups and the majority of them were from two health authorities – Vancouver Coastal Health and Fraser Health Authority. Many of the issues raised by the participants are echoed in the Ombudsperson's report and in other studies on BC's home support system.<sup>56 57 58 59 60</sup> It is, at the same time, important to note that both health authorities are primarily urban and may not reflect the experience of clients, care givers and health providers from rural and remote communities.

### 4.1 The Changing Nature of the Care Experience for Clients, Family Caregivers and Front-line Staff

#### 4.1.1. Person-Centered Care is Not an Option

*“There are so many things I'd like to do in the day, but I can't or don't have time. If something isn't in the care plan,*

*I can't do it, no matter how simple it is. You build up a relationship and want to help – that's why we got into this work. I can't chat or socialize with clients at all, take out the garbage, make toast or a snack. If I notice they are out of milk or eggs, I can't do even just a little bit of shopping.*

*"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)**

**T**HE INCREASED PRESSURE on the health authorities to provide more services with limited resources has resulted in a system of very rigid protocols for the community health workers, who are authorized to perform only a very limited number of prescribed tasks. These are outlined in the care plan developed by the case manager. The community health workers are informed of the specific tasks that they are authorized to perform and if they engage in activities not on the care plan, they will not be covered for liability or injury and may be reprimanded by their supervisor. Access to the care plan itself (which includes the client's health history and diagnoses) varies considerably from one area to another. As one Community Health Worker notes,

*"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)**

Participants in the nursing and physician focus groups agreed that the lack of flexibility in the community health workers' role and their limited access to patient information is problematic:

*"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)**

*"Really what most people need is some more flexibility about how a community health worker uses their time. The bigger question is: 'What does a person really need in order*

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 focused on the task... not actually thinking about the person.

(Community health worker)

*to be able to stay in their own home? It goes beyond help with medications and personal care.”*

**(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)**

In all of the focus groups, concerns were raised about the lack of access to basic services like meal preparation, housekeeping and laundry. One of the participants in the physicians’ focus group was particularly concerned about the lack of focus on physical exercise, which she saw as one of the only activities that actually improves cognition.

#### **4.1.2. Social Support No Longer Part of the Community Health Workers’ Role**

**D**ESPITE ALL OF the evidence on the importance of social support in ensuring that seniors can continue to live healthy and active lives in their own homes, providing this support is no longer part of the community health worker’s role. As one community health worker commented:

*“...our clients suffer because certain tasks have been removed from the care plan...and socializing is no longer allowed because there isn’t time for that... there is less chance to really know what is going on with the person.”*

**(Community health worker)**

A family caregiver offered this insight:

*“Home support workers need to have the ability to be a companion...to engage their clients. The social connection is very important and home support workers should be encouraged to develop skills to draw someone out, have a meaningful exchange, and share meaningful activities. Of course this requires proper assessment of the client so that the home support worker is doing the appropriate thing.”*

**(Family caregiver)**

One of the nurses pointed out that socially isolated seniors often end up in emergency:



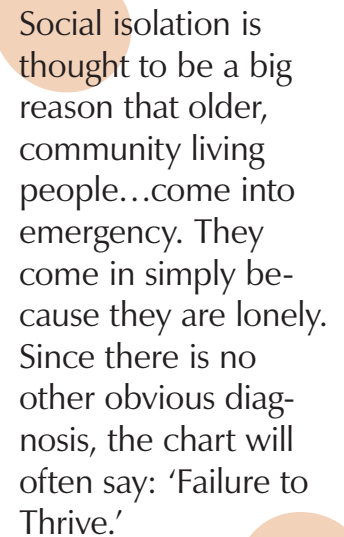
*“Social isolation is thought to be a big reason that older, community living people...come into emergency. They come in simply because they are lonely. Since there is no other obvious diagnosis, the chart will often say: ‘Failure to Thrive.’”*

**(Registered nurse)**

Given the pressures on the home support system and the limited time community health workers have to address their clients’ needs for social support, it would seem reasonable to expect, that at a minimum, community health workers would be encouraged to connect their clients with the social support services and resources available in the community. However, as one of the community health worker focus group participants noted:

*“Home support workers are actually discouraged from sharing information about community services like meals on wheels, adult day services and HandyDART 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)**



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)

### 4.1.3. Meaningful and Trusting Relationships between Workers and Clients Less Likely

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)

IT IS BROADLY acknowledged that continuity is important to good quality outcomes for the person receiving care. Continuity makes it possible for CHW – like other members of the primary and community care team – to get to know their client, establish a relationship with them and monitor and report on any changes in their health status.<sup>61</sup> However, continuity is more difficult to achieve with a rotating, short-term schedules and a high proportion of casual workers. Many visits are very short (some visits are less than 30 minutes depending on the task) so as to maximize the number of clients that can be served on each shift. The result: today's community health workers are less likely to have the opportunity to develop a meaningful and trusting relationship with their clients. As one worker put it:

*“You have to build a relationship with the client to get them to open up because some of them just don't want to tell you that they're having medical issues because they don't really know you, don't want anyone to worry....”*

**(Community health worker)**

For the family caregiver, who has to re-establish a relationship with each new worker who arrives at the door, 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 participants in the nurse focus group 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 recognize that this lack of continuity is problematic and in recent years they have introduced “cluster care” as a way of providing more consistency. With cluster care, instead of scheduling clients for each service, community health

workers are part of a healthcare team who have a caseload of clients who live in the same neighbourhood or building. In theory at least, the community health workers have more flexibility to decide how much time to spend with each client depending on their needs that day. While the community health workers see the benefits of moving to “cluster care,” they raised concerns about this model as well. Community health workers reported that they still feel rushed and have limited time to respond flexibly to client needs because of the increased number of clients (many with complex needs) they are now expected to serve.

#### **4.1.4. Family Caregivers Are Not Recognized or Supported**

**A**T PRESENT OUR community health care system provides little support for informal caregivers, even though family caregivers play a crucial role in maintaining at-risk older persons in the community and should to be viewed as part of the care team.<sup>62</sup> The participants in the family caregiver focus group talked at length about the lack of recognition of the needs of family caregivers by the health authorities and home support agencies. As one woman who was a primary caregiver for her husband recalled:

*“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. Daycare services were recommended and were available so there was an opportunity for respite and for me to continue to work. Things are quite different now...and services are contracted out which means quality of service varies. We ended up foregoing public services because it was no longer helpful to us.”*

**(Family caregiver)**

One of the participants at the seniors focus group described a lengthy and frustrating process that her family had to endure before a community health worker could visit:

*“Because ‘Bob’ started to need help with transfers, VCH had a bunch of conditions we needed to satisfy...installation of a lift, purchase of a hospital bed, renovations to existing bathroom to provide a wheel-in shower. The reason was for*

*safety of the workers which is understandable but it took a long time and we were expected to pay for all this...*

**(Senior)**

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.'

(Family caregiver)

Another family caregiver talked about how the health system was not able to appropriately support her mother to care for her father at home:

*"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)**

## 4.2 The Focus Group Participants' Perspective on the Need for Systemic Change

### 4.2.1. Care, Reactive Not Proactive

THE PHYSICIAN, NURSE and community health worker focus group participants commented that increasingly, instead of being part of a proactive plan to support seniors to live well in their own homes for as long as possible, care is usually put in place in response to a crisis. They also noted that there is very little focus on restorative care for people who are at risk of functional decline but who, if supported to develop their skills and confidence to do things for themselves could be more independent, would have better health outcomes and reduced service costs. As one of the community health workers commented, although there is some recognition 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)

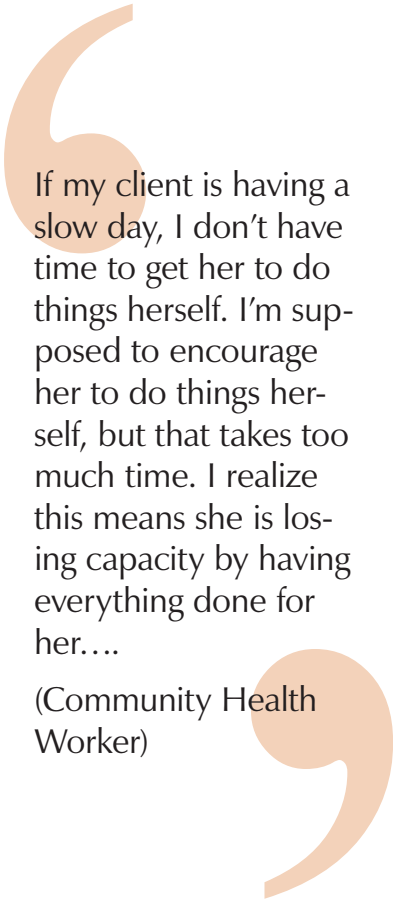
A recently retired family physician reflecting on the Danish law that requires everyone 75 years old or over be proactively offered services once a year had this to say about the system in BC:

*“If everyone automatically were to get assessed at age 75 or 80 years old, to see how they are managing in their environment, it would normalize the process, and older people might be more accepting of preventative measures earlier in the trajectory of aging...a lot of our interventions are reactive rather than proactive earlier on.”*

(Physician)

Focus group participants were also clear that older adults living at home with moderate needs were not offered access to services. One community health worker put it this way:

*“If a client has been in the system for a while, they still get services but if there is someone coming from hospital or someone who is just strictly needing a bath twice a week or*



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)

*meal preparation...we don't get those anymore....clients with moderate needs.”*

**(Community health worker).**

For people with dementia, the lack of support for early interventions is particularly important. As noted in the comment below, community health workers need to establish a relationship with their clients before their dementia reaches a point where they experience “stranger anxiety.”

*“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 – say half an hour 3 or 4 times/week 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)**

Family caregivers agreed that person-centered, early interventions were key to supporting the person with dementia to remain at home for as long as possible.

*“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 ... 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. In this example the family decided that this wasn't working for them and one of the daughters has put her life on hold and moved in...but this is not always possible.”*

**(Family friend)**

#### **4.2.2. The System is Ill-equipped to Deal with Increasingly Frail and Complex Clients**

**F**OCUS GROUP PARTICIPANTS commented on the increasing pressure on the home support services system to provide medically-complex care services in the home or in assisted living buildings

– services which historically have been performed in hospital or extended care settings.

*“If you actually looked at the trend in care provision, you’d notice that what used to happen in hospitals now happens in extended care and what used to be in extended care is now at home in the community. There is no such thing as intermediate care anymore and the scary thing is community health workers are expected to take care of these people without adequate lifts or training for certain types of care.”*

**(Registered nurse)**

Participants in the community health workers focus group were very 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, but we still have to pay out of pocket for the specialized training.”*

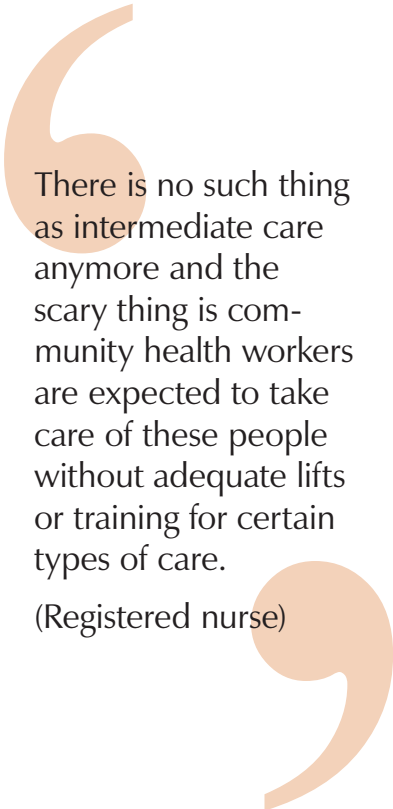
**(Community health worker)**

The participants at the nurse focus group agreed that community health workers increasingly get requests to perform tasks that are traditionally nursing tasks. In many cases community health workers need more coaching and support than is available from RN’s working in home care, because of the workload of the home care RNs. In some other instances when the task is well beyond the scope of the community health worker, the care plan may be modified so the community health worker can deliver the care, but this may be in ways that are less than optimal for the client.

*“If tasks such as insulin injections are considered beyond the scope of the community health worker, and are not picked up by others, decisions (compromises) are made to change the protocol for the patient to give insulin in a different (oral) fashion, resulting in a system of ‘risk mitigation’ and not a system of ‘optimal care’. This is not person-centred care or ethical.”*

**(Registered nurse)**

The nurses also agreed that employing more LPNs could address some of the gaps in the current home support system. An LPN



There is no such thing as intermediate care anymore and the scary thing is community health workers are expected to take care of these people without adequate lifts or training for certain types of care.

(Registered nurse)

Palliative and home and community care are two different systems. It is difficult to get a frail older person into community palliative care if he is not actively dying, and when the next health crisis comes it is already too late....

(Physician)

who was part of the focus group said:

*“Given the different levels of client needs and the goal of optimizing community-based health care, 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. Also, employing LPNs is cost effective. It surprises people when they learn that LPNs make only \$3 to \$5 more than community health workers.”*

(Licenced practical nurse)

To better support their palliative clients, physicians would like to have the option of supporting their patients to receive palliative care at home, but to do this, multi-disciplinary teams of community health workers and nurses would need to be put in place. As one physician noted, for palliative care to work:

*“The home and community care team need to be there to support that person in the last stage, in the last few days, which can’t happen these days... And I think that 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.”*

(Physician)

Another physician talked about the problems that arise in co-ordinating care because palliative care is not integral part of the home and community care system:

*“Palliative and home and community care are two different systems. It is difficult to get a frail older person into community palliative care if he is not actively dying, and when the next health crisis comes it is already too late and he has been sent to hospital against his wishes.”*

(Physician)

Similar problems arise if a senior has a mental health problem as community mental health services are also a separate program (i.e. not part of Home and Community Care). This makes it more difficult to access services and co-ordinate care.



### 4.2.3. The Shortage of Case Managers Creates a Bottleneck in the System

**T**HE CASE MANAGER plays a pivotal gatekeeper role in home and community care. Based on the experience of the focus group participants, clients cannot access services until they have been assessed by a case manager and a care plan is developed. All the focus groups talked about the importance of the case manager's role in accessing and co-ordinating services and about the fact that there is a bottleneck in the system due to the shortage of case managers. One of the participants in the physician focus group had some personal experience to share:

*"It can...take a lot of time from the time you refer. I'm just thinking of my mother-in-law on the north shore. One of her sons made the call last Fall. She's moderately demented and heading towards severely demented, lives in her own home and has absolutely no insight. And the kids are kind of taking her for coffee and to dinners and stuff like that. She really needs some regular home support ... She doesn't shower anymore and that kind of thing. I asked her son about 3 or 4 months later, I said, 'you made that call. Hasn't she been assessed yet? And he said, 'We're still waiting!' It moves very slowly."*

**(Family Physician)**

The community health workers agreed the shortage of case managers contributed to their frustration when trying to report that a client's health had declined and that the individual needed additional care.

*"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)**

The caregiver focus group participants had similar complaints about the shortage of case managers. A daughter providing round-the-clock care to her Mom who suffers from advanced dementia recounted her experience with the system:

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

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

(Family caregiver)

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...

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

*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.*

*“I took two years to get Mom into adult day services and I was initially informed that Mom didn’t qualify for these services because she lived in a private-pay assisted living residence. I didn’t want to upset the caseworker for fear that I would be inviting discrimination. I’ve now applied to place my Mom in a care facility that will cost us \$6500/month.”*

**(Family caregiver)**

The coordinator for a group of caregivers in Metro Vancouver area also talked about the challenges caregivers experience in getting timely and proactive support from a case manager:

*“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 clients once a year, but due to very heavy caseloads they may only check in every two years. I always advise family caregivers to let case managers know when there is a change in the situation of their care recipient.”*

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

On the other hand, the research evidence is quite clear: one of the best ways to reduce institutionalization rates for persons living with dementia is to have the case manager actively involved with the person with dementia, the family caregiver and the community health worker.<sup>63</sup>

#### **4.2.4 Effective Communication and Teamwork Not Prioritized in the Current System**

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

**(Community health worker)**

**I**N THE PAST a community health worker could contact a case manager directly if they had a concern about a client; now they must go through their supervisor. Both the nurses and commu-

nity health workers talked about the challenges that community health workers experience when trying to get their supervisors and/or the case manager to respond to their concerns. From the focus group with community health workers, it was abundantly clear that they had little trust that their concerns were even being forwarded to the case manager and that their input was valued by either their supervisor or the case manager.

In addition, 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. As a consequence they are often ill prepared when they begin to provide care to a new client. The nurses agreed with the community health workers that this was very problematic:

*“The job of the home support worker is extremely challenging now because they don't have access to a lot of the background medical information and history to go on due to privacy issues. And with a breakdown of communication, the community health worker may not be informed that a client poses a risk because of mental illness, communicable disease etc.”*

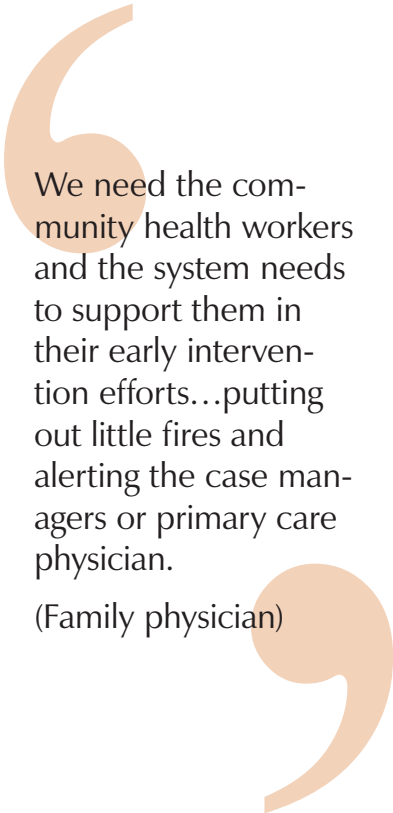
**(Registered nurse)**

One of the physicians talked about the importance of recognizing the community health workers as valued members of the team:

*“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)**

At the community health workers focus group, there was a suggestion that monthly team meetings might be a way of facilitating more effective communication between the community health worker, their supervisor and the case manager. One of the community health workers from a cluster care site described their team meetings where the case manager, supervisor, community health workers, and a BC Housing representative shared information and then passed that information on to the scheduler. However, this seemed to be more of the exception than the rule. Both the community health workers and nurses felt that a philo-



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)

sophical shift is needed to ensure that care plans are regularly updated and shared with the community health workers, and that community health workers are actively encouraged to report any changes in their client's conditions and are provided with feedback when they raise these concerns.

*"... The care plan should be regularly updated and easily understood. Any new or additional information regarding the client's needs should be made accessible to the home care worker, especially before their first visit."*

**(Registered nurse)**

There were also concerns raised about the lack of information sharing with physicians and the importance of this information for the physician to be able to anticipate the future care needs of their patients:

*"As a busy family doctor, I would advocate for a written summary of the case manager's assessment and potential resources and {client} needs down the road...There is nothing like this currently and...as I provide longitudinal care, I will be involved in planning options down the road and it would be extremely helpful to have the case manager's documentation."*

**(Family physician)**

A related issue is the current protocol requiring that in response to a health crisis, the community health worker must call 911. Often this action results in an unnecessary trip to emergency.

*"A specific frustration physicians have is with the rules that home support workers must follow if a crisis or an acute medical issue comes up. They have a very narrow protocol and that is to call 911. That is what they have to do. And then someone lands in Emergency when a nurse practitioner or physician could have been called to attend... And the doctor wouldn't have to hear after the fact that their patient was admitted (yet again) and was being worked up for all kinds of things...they were actually probably managing quite nicely before all that. Again, it speaks to the inflexibility around the healthcare workers and the system protocols."*

**(Physician)**

Based on the feedback from the focus group participants, it is clear that more effective strategies for ensuring the appropriate

feedback, collaborative forms of communication and teamwork are needed for community health workers to play an effective role in monitoring changes in their client's health status and helping to avert health crises.

## 5. Discussion 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)

**A**LTHOUGH THE OFFICIAL policy of the Ministry of Health is to support seniors to live independently in their own homes for as long as possible, the health authorities and home support agencies have been left largely on their own to deal with a higher volume of increasingly frail and culturally diverse clients with higher medical, social and emotional needs. There has been no proactive planning at the provincial level for how to better integrate home support with other community and primary care services. Nor have steps been taken to address the need for restorative care and preventative services that have proved so effective in other jurisdictions at averting health crises, reducing utilization of acute and residential care, and controlling cost increases.

Instead, in response to growing demand and limited resources, clients with more moderate needs are no longer eligible for home support and 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 and establish trusting and meaningful relationships. As a result, person-centred care and care continuity -- critical good quality outcomes -- have been severely compromised. And although clients have higher and more complex medical needs than in the past, it is more, rather than less, challenging today for a community health worker to communicate their concerns about a client's well-being to a case manager and/or get the support that they need from a home care nurse. Collaborative communications and teamwork appears to be the exception rather than the rule.

The majority of home support clients rely on the support of informal family caregivers, and yet the system is not set up to provide the caregivers with the respite and social support they require. And despite the evidence that social support is critical to healthy aging, social support is no longer part of the community health workers' role. Community health workers are not even allowed to help their clients and family caregivers access information about the social support services available in their local community. In many ways we are dealing with a broken system. As a physician commented in the focus groups:

*"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!"*

**(Physician)**

It seems clear that the home support agencies and/or health authorities cannot resolve these challenges on their own. What is missing and most needed is leadership from the provincial government. 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.”<sup>64</sup> 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. 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 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.***

From 2009-10 to 2013-14, the number of clients receiving home support services from the health authorities increased from 32,768 to 38,802, and costs increased by \$49 million, an increase on average of 3.25 percent a year.<sup>65</sup> This increase effectively meant that the same number of home support clients received services in 2013 as in 2001, and yet over those 12 years, there has been a 49 percent increase in the number of seniors over 80 (see discussion on page 6 of this report). While it is beyond the scope of this paper to estimate the exact service level increases

required to meet the current and future needs for home support and related professional services, it is clear they are significant and substantial. This is why it is important to tie funding increases to system changes that have proven effective at supporting healthy aging, averting health crises, and/or reducing the utilization and costs in acute and residential services.

**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 prior to their first visit, and 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 physi-*



*cian/ 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.*

## 6. Conclusion

IN FEBRUARY 2015 the Ministry of Health released a strategic planning framework that is very much in line with the recommendations of this report. The Ministry’s document calls for the creation of a “range of multidisciplinary practices across communities” open 24/7, focused on both the primary health care and social needs of older adults and inclusive of community health workers, nurses, allied health professionals, family physicians, specialists and community social services.<sup>66</sup> There was also strong commitment in the document to develop an “integrated health system that works for patients” and not just providers, and an invitation for broader input on specific policy proposals and directions. Our report and recommendations provide some very concrete ideas for how to make the vision outlined in the Ministry of Health’s strategic policy framework a reality on the ground in terms of how home support services are delivered and integrated with other home and community care services, multidisciplinary primary care, and community based social supports for seniors.

## APPENDIX A

### The Focus Group Participants

The Physician Focus Group (Total of 6 physicians participated)

- *Family physician, working in geriatric care in Vancouver*
- *General Practitioner, worked in nursing homes and currently has family practice in Vancouver*
- *Family physician, working in geriatric care in Vancouver*
- *General Physician, working at a full-service health clinic in Vancouver*
- *General Practitioner, retired Medical Health Officer with Vancouver Coastal Health*
- *Family physician*

The Community Health Worker Focus Group (Total of 10 CHWs and representatives from the BCGEU participated)

- *801 scheduler, Vancouver Island, non-profit*
- *801 CHW, Vancouver Island, non-profit*
- *803 CHW, Lower Mainland, Occupational Health & Safety Worksite Representative*
- *803 CHW, Lower Mainland, for profit*
- *803 CHW, Lower Mainland, non-profit*
- *804 CHW, Fraser Valley, for-profit*
- *804 CHW, Fraser Valley, for-profit*
- *804 scheduler, Fraser Valley, for-profit*
- *804 CHW, Fraser Valley, for-profit*

Nurse Focus Group (Total of 9 nurses participated)

- *RN, CRN Home Support*
- *LPN, Fraser Health*
- *LPN, Lower Mainland,*
- *RN, Case Manager, Fraser Health*

- *RN, VCH, Retired from a geriatric assessment clinic, currently working as a nurse at Adult Day Centre in Metro Vancouver area*
- *RN, Geriatric Assessment Clinic, Fraser Health*
- *RN, Primary Care Seniors' Clinic, Fraser Health*
- *RN, Clinical Coordinator in Home Support, Vancouver Coastal Health*
- *RN, Clinical Resource Nurse Home Support, Fraser Health*

Seniors Focus Group (Total of 11 seniors participated)

- *Seniors from Highlands United Church in North Vancouver receiving home support or who had friends receiving home support*

Caregivers Focus Group (Total of 8 caregivers participated – 3 via e-mail)

- *Coordinator of Burnaby Caregivers Group*
- *Burnaby caregiver group – 4 participants*
- *North Vancouver caregivers via e-mail – 3 participants*

## APPENDIX B

### Sample Interview Questions

1. Could you describe your experience with the system for delivery of home support/home health services? Can you give us some examples of what is and what is not working?
2. Many people at a recent roundtable on “The Future of Home Support” commented on the Health Authorities’ focus on providing home support services for a growing population of frail, medically-complex clients who would otherwise be in hospital or residential care. At the same time, older people with more moderate needs are not receiving the extent of the services they need. Is this your experience?
3. Do you feel that you need additional training/expertise/support to effectively care for the more medically complex and frail clients you are now serving?
4. In addition to the care you provide, do you see gaps in services for your clients related to “non-personal health care” services such as housekeeping, laundry, meal preparation, social visits, emotional support, physical out-of-door exercise, etc.?
5. In this question we would like to get your ideas about key changes needed to in home support/home health to: a) improve communication and co-ordination among care providers; b) provide more mentoring and support to front line community health workers; c) shift to a restorative model for service delivery (i.e. where seniors are supported to become more independent and connected to the community). What are the barriers to making these changes? What would work better?
6. Is there anything we’ve missed? Are there any other strategies you could suggest for providing more effective coordination of home care to seniors with chronic conditions and to their family caregivers - who also may have health issues of their own?

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