

Caregivers in Distress

More Respite Needed



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As I continue to listen to seniors and their caregivers, one of the issues I hear about consistently is the increasing strain on unpaid caregivers, and family caregivers in particular. Indeed, one of the unintended consequences of our desire to live as independently as possible, for as long as possible, is the impact this can have on our spouses and children as they become our caregivers.

The stories I hear are both heart-warming and heart-breaking as unbelievably committed husbands and wives steadfastly and stoically care for their aging spouses. There are sons and daughters, some of whom are seniors themselves, demonstrating a deep commitment to keeping their moms and dads at home. I see and hear about the very meaningful fulfillment this caregiving brings, while I also learn of the frustration and exhaustion that caregivers so often experience as well. When I looked at the data for the 31,084 seniors in this province who are enrolled in the home support program, I found that 29% of caregivers were assessed as experiencing actual distress. This means that about 9,000 individuals reported being angry, depressed, or in conflict because of caring for their loved one and/or believe they would not be able to keep performing their caring activities.

Clearly, this is a wake-up call. Unpaid caregivers, most of whom are family members, are often the only thing standing between a senior's continued ability to live at home and placement in residential care. If we cannot find a way to support these caregivers, especially those who are in distress, we will find that demand will increase on residential care and acute care as seniors can no longer be supported at home.

There is little question that caregiving is stressful. The physical strain of caregiving is exacerbated by the emotional toll of watching your loved one becoming increasingly frail. The question of what can be done to relieve this stress is not a simple one to answer, in part because individual situations can be so varied and some of the things that are causing the stress simply cannot be fixed. However, there are a number of improvements that could be made that could significantly alleviate caregiver distress, and that is the guiding philosophy of this report.

This report looks at the home and community care system in B.C. and analyzes data to find who the distressed caregivers are, why they are distressed, what supports are available to them, and if they are accessing these supports.

Through the analysis, I identified a number of concerns, including:

- 29% of caregivers are in distress, one of the highest reported rates in Canada
- 54% of caregivers would benefit from respite services such as an adult day program, home support or respite bed, yet:
 - Only 7% used an adult day program in the last seven days
 - Only 53% used home support in the last seven days
 - Only 11% used a respite bed in the last year

I was concerned to find that clients with a distressed caregiver are less likely to have received a home support visit in the last seven days than clients without a distressed caregiver. There is no objective evidence to explain this finding, but clearly it is an area we need to focus on. In addition, services such as home support have not kept pace with the increase in the seniors' population, while others are actually decreasing, such as adult day programs and respite beds.

As well, I compared us to our neighbouring province of Alberta, and found B.C. has a 45% greater rate of caregiver distress, yet clients in Alberta are accessing more home support for less complex needs. The Alberta comparison also revealed an opportunity to significantly reduce emergency department visits and hospital admissions by providing high intensity adult day programs, something I hope B.C. will adopt.

As you read through this report, you will find the evidence to support the case that we can be doing more to support distressed caregivers by increasing their access to respite through three provincially funded supports: adult day programs, home support and respite beds.

We know that increasing these supports will not eradicate caregiver distress. Respite is just one of many possible interventions. However, it is a critical step in ensuring that caregivers receive as much support as possible in the vital and often overlooked work they are providing.

Sincerely,



Isobel Mackenzie
Seniors Advocate
Province of British Columbia

Introduction

There are over 30,000 seniors in British Columbia for whom the ability to live as independently as possible is enhanced by the contributions of an unpaid caregiver. Without the support of these unpaid caregivers, who can be spouses, or other family members, neighbours, friends or volunteers, the responsibility and concomitant cost for the services they provide would fall to governments at the local, provincial and federal level. A 2009 economic study estimated that on a national level, the value of unpaid caregiver labour is \$25 to \$65 billion per year.¹ B.C.'s share of this could reasonably be estimated at \$4.1 billion in 2015 allowing for population growth and inflation.

In addition to the labour costs of the actual caregiving, those who are supported at home by an unpaid caregiver are less likely to be referred to residential care. Ninety-seven per cent of seniors assessed as eligible for provincially subsidized home support report an unpaid caregiver assisting them in some aspect of care or support. Fifty-three per cent of these seniors are as complex as those living in residential care, although they remain living at home. These highly complex seniors are receiving, on average, 24 hours of care per week from an unpaid caregiver.

There is evidence that supporting the caregivers who are caring for these seniors is a significant predictor of whether the senior they are caring for will ultimately be placed in residential care. This latter hypothesis is supported by the findings of 10 randomized controlled trials that indicate a 40% reduction in the odds of placement in residential care when caregivers and clients are offered

structured, intensive and multicomponent choices of services and supports.²

Support for caregivers can come in many forms. Some caregivers find relief when they can participate in support groups to share their experiences with fellow caregivers, others need help navigating the system, while some require relief from the financial burden and impact on their work life. Some caregivers require a variety of these supports to successfully cope. Almost all, however, require periods of respite from the person for whom they are providing the care.

This report is focused on one aspect of support for caregivers – providing respite from caregiving duties. In B.C., this respite is substantially achieved through three provincially funded programs: adult day programs, home support, and respite beds.

Supporting caregivers through respite is key to ensuring they are able to continue their caregiving role. The argument for doing this is



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not only one of compassion for the caregiver, it also represents a strategic investment in the healthcare system.

However, an examination of data for the key respite programs in B.C. show that more could be done to support caregivers with this crucial service.

What is Respite?

Respite care has traditionally been defined as a short-term and/or temporary break from caregiving duties achieved by:

- offering regular access to a place in the community that the care recipient can go on a daily basis to be supported by care staff;
- bringing in support personnel to the home to take over some or all aspects of care provided; or
- temporarily moving the care recipient to a residential care bed to receive 24-hour professional care to facilitate a prolonged period of rest for the caregiver.

It is crucial to recognize that respite is not a service, it's an outcome. It offers a hiatus for the caregiver, a chance to re-charge, to access information and resources, to avoid burnout



or crisis, to leave the home to socialize or run errands, and ultimately is a key support that strengthens a healthy relationship between the person receiving care and the caregiver. Depending on the type of respite, the care recipient can benefit by having an opportunity to socialize and engage in new activities, and receive care that the primary caregiver can't normally provide such as occupational and physical therapies.

In B.C., subsidized respite services can only be accessed after assessment and approval by a health authority case manager. There are three main types of government-subsidized respite in B.C. as described below.

Adult Day Program (ADP) – ADPs provide up to seven hours per day of respite to the caregiver. In addition to addressing the needs of the caregiver, ADPs also offer services for the client in a safe environment including social activities, meals, and sometimes health services such as rehabilitation. In most cases, a senior must be unable to function independently and have been assessed as requiring adult day services as part of their care plan. Transportation to and from the ADP location may or may not be provided. ADP clients can arrange standing transportation via HandyDART, which costs about \$5 roundtrip. Fees for ADPs usually range from \$5/day - \$10/day. This rate is sometimes waived or scaled based on income, but the maximum allowed by policy is \$10 per day, regardless of income.

In-Home Respite – In-home respite is offered through the standard home support program. The community health worker comes to the home allowing the unpaid caregiver to take a break elsewhere in the home or outside of the home. To be effective respite needs to be offered in a block of three or four hours at a time that makes sense for the caregiver. For

some clients, the respite offered is an overnight shift to allow the caregiver an opportunity for uninterrupted sleep. In addition to the “respite” offered by allowing the caregiver to leave the home, home support in all forms also provides respite from providing actual care whether that is the 30 minutes it might take to feed a client or the hour it might take to get them up in the morning, washed and dressed.

Home support clients are assessed according to their income and may pay a “per diem” rate which could be a few dollars, or if their income is high, the full cost. If either the client or their spouse has any income that is considered “employment income” the maximum they will pay, regardless of the amount of the employment income, is \$300 per month.

Respite Beds – This is respite where the senior leaves the home and stays in a respite bed in a residential care facility for a period of up to 30 days. Facilities may have required minimum stays or advanced booking requirements. Respite beds are not available in every care home, and some beds are not solely reserved for respite use but are rotated in and out of full-time use depending on demand. The use of respite beds is usually dependent upon availability, rather than limitations on frequency of use or financial caps. Users of this service pay a fee of \$32.50 per day regardless of income, as mandated by policy. If this fee creates a financial hardship, policy allows for it to be waived.

Who Needs Respite?

Capturing the total population of caregivers who need respite services is difficult. However, for the purposes of this report we have chosen to look at the 31,084 seniors who have been assessed as eligible for health authority provided home support services. It is assumed

that the majority of seniors who would benefit from and qualify for publicly subsidized respite services would be enrolled in the home support program. Excluded will be those who have opted to engage only private services, those who have been deemed ineligible for the program or those who are either unaware of or have resisted/declined enrollment in the home support program.

Seniors who qualify for home support services have been assessed using the RAI-Home Care (RAI-HC). This assessment is completed by a health authority case manager, and all clients are re-assessed as needed,

or at a minimum once per year. The RAI-HC is an internationally validated assessment tool that looks at levels of cognitive and physical function, family and community supports, current physical environment, health conditions, mood and behaviour, medications and service utilization among other clinical measurements. The RAI-HC assessment is an objective measure of need, and is used in conjunction with other tools and data to determine the care needs of the senior assessed.

Unless otherwise noted, data used in this report represent the RAI-HC for 31,084 home support clients in B.C. for the year April 1, 2012 to March 31, 2013 (2012/13). While these data will not capture the potentially thousands of seniors who are being cared for outside the home support program, it does focus on the most physically frail seniors who are more likely of moderate to low income.

97% of B.C. seniors eligible for home support also receive support from an unpaid caregiver

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Analysis of these data showed that almost one-third of caregivers are in distress. Clearly, this demonstrates caregiver distress is real, and could have a significant impact on the ability of seniors to continue to live independently. In addition to showing 29% of clients have caregivers with distress, the data confirmed:

- 40% of clients are aged 85 or over
- 34% of clients have a diagnosis of dementia
- 97% of clients report the presence of an unpaid caregiver in their life
- 45% of clients live with the person who is their unpaid caregiver
- 55% of those clients who have the caregiver living with them have their spouse serving as their primary unpaid caregiver
- The higher the level of care needs, the more likely the caregiver is a spouse
- The average hours of unpaid care provided is 19 hours per week and this increases to 24 for complex clients and increases again to 30 for those caregivers who are in distress.

While respite is arguably important for all caregivers, it is exceedingly important for the 29% of caregivers who indicate they are in distress.

Causes of Caregiver Distress

To determine the most effective supports or programs it is important to understand the systemic issues that lead to caregiver distress. To achieve this, the OSA combed the RAI-HC assessment data looking for unique characteristics of clients whose unpaid caregiver is in distress.

We found the strongest predictor of caregiver distress is the number of hours of care

provided by the unpaid caregiver. In B.C., the odds of having a distressed caregiver are four times more likely for clients receiving 20 or more hours of unpaid care per week than for clients receiving six hours or less. This is the reason we have focused on the issue of respite services for our first report on caregivers.

Almost 1/3 of caregivers are in distress and they provide an average of 30 hours of care per week

Every hour of respite provided relieves an hour of care provided by the unpaid caregiver and evidence shows that lowering the number of hours of care provided by unpaid caregivers will systemically lower caregiver distress.

The second and third strongest predictors link to the condition of the person receiving care. Clients with behavioural problems that are worsening and/or who have significant cognitive impairment link strongly to caregiver distress. Twenty-four per cent of assessed individuals have these conditions, however this increases to 44% for distressed caregivers.

The fourth most linked predictor of caregiver distress is the potential of depression. Our RAI-HC analysis showed that where there are significant symptoms of depression present in the care recipient, the caregiver is almost twice as likely to report distress. In addition, for the whole home care population the prevalence of potential depression in clients is 19%, but where the caregiver is reporting distress that percentage rises to 31%. This factor cannot be underestimated. Caring for a depressed person can be extraordinarily difficult because they are less likely to engage in everyday activities, be companionable or show initiative to perform tasks that may be within their cognitive or physical ability range.

What Did We Examine?

There are over 200 indicators contained in the RAI-HC. For this study we primarily looked at the following:

- **Method for Assigning Priority Levels (MAPLe)** score, an algorithm that uses dozens of items within the RAI-HC to assign a numerical value to the overall complexity of a client assessed. MAPLe scores range from 0-5. MAPLe scores have been shown to accurately predict caregiver distress and to demonstrate that those clients with higher MAPLe scores (4/5) are more likely to be admitted to a residential care facility within 90 days of assessment.
- **Cognitive Performance Scale (CPS)** measures, on a scale of 0-6, the ability of a person to make their own decisions, manage medications and money and organize their day. Someone scoring in the “mild” cognitive impairment range (1-2) is likely to manage reasonably well, but may require assistance from a caregiver with some daily tasks, someone scoring 3 or above needs close supervision to prevent getting lost and direction to carry out daily tasks.
- **Activities of Daily Living (ADL) Scale**, measures a person's performance in tasks such as bathing, toileting and activities related to their personal care. A person can be very limited in their ADLs due solely to low physical function, or low cognitive function, or a combination of both. The scale for ADL (self-performance hierarchy) ranges from 0-6. A score of 3 or higher generally describes a person who is not fully independent and must have physical assistance to complete these tasks. This could, for example describe someone with almost no ability to weight bear without a walker or confined to a wheelchair, someone who is blind or someone with advanced arthritis. As the scale progresses, a person scoring 6 is fully dependent on another to complete these basic tasks.
- **Diagnosis of Dementia:** The RAI-HC records dementia as being present if a medical doctor has made a formal diagnosis. In some cases, formal diagnosis by a physician could be pending at the time of assessment and so the real number of people with dementia could be higher. Conditions such as Alzheimer's, multi-infarct dementia, organic/chronic brain syndrome, Picks, Creutzfeld-Jacob and Huntington's are included in a dementia diagnosis.
- **Depression** is a mood disorder and is associated with significant morbidity. Associated factors include poor adjustment to one's living situation, functional impairment, resistance to daily care, inability to participate in activities, isolation, increased risk of medical illness, cognitive impairment, and an increased sensitivity to physical pain. The RAI-HC measures mood using a range of indicators that include verbal and non-verbal expressions, the level of involvement in activities, as well as the prevalence and duration of the features. This measure is called the Depression Rating Scale (DRS).



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The scale ranges from 0-14 and is created by combining the presence of targeted symptoms along with the intensity and duration of those symptoms. A score of 3 or more indicates the potential or actual presence of depression.

- **Caregiver Distress** is defined in the RAI-HC as when the primary unpaid caregiver expresses, by any means, either that he/she is distressed, angry, depressed, or in conflict because of caring for the client; or, the caregiver, client, or clinician believes that a caregiver(s) is not able to continue in caring activities. The latter can be for any reason, for example: lack of desire to continue, geographically inaccessible,

other competing requirements (child care, work requirements), personal health issues.

Based on the above, a target population of clients who might benefit from respite was identified as:

- MAPLe 4/5 (includes CPS 3 or more)
- ADL 3 or more
- Diagnosis of dementia
- DRS 3 or more

The most critical of these are clients with MAPLe 4/5, CPS 3 or higher, and ADL 3 or higher. This population represents 54% of home support clients.



What Did We Find?

While 54%, or over 16,000 seniors, could benefit from some form of respite, the data confirmed:

- 11% or less have used a respite bed in the last year (health authority data, 2013)
- Only 7% participated in an ADP in the last seven days
- Only 53% used home support in the last seven days
- 29% of clients have a caregiver reporting distress
- 38% of clients MAPLe 4/5 have a distressed caregiver

For the clients with distressed caregivers:

- Only 9% attended an ADP
- Only 47% received home support in the last seven days

Taken in totality, these data show an extraordinary gap between those caregivers who would potentially benefit from respite services and those who are actually receiving them. There will logically be some cases where caregivers are coping despite the complexity of the client they are caring for. However, the 29%, or 9,000, who are reporting distress clearly need help, and the data show a wide gap between caregivers in distress and utilization of respite services available to support them.

Assessing the reasons for the gap and possible solutions that could ensure caregivers are linked to respite resources revealed a lack of standardized definitions, assessments, payment schedules and access both within and across health authorities.

Summary of Key Findings

	All Home Support Clients (n=31,084)	Clients With Caregiver Distress (n=8,993)
Residential Care Respite in past year	11%	Not available
ADP in last 7 days	7%	9%
Home Support in last 7 days	53%	47%
Caregiver Distress	29%	100%

Adult Day Programs (ADPs) – Challenges and Opportunities

ADPs can be a unique respite service that benefit both the caregiver and the person receiving care. ADPs can vary in the type of supports and services they offer and in the complexity of client they can accommodate. In B.C., the focus has mostly been on basic ADPs offering social type supports with limited support from healthcare professionals. This arrangement minimizes the ability to properly serve those with more advanced dementia and/or low physical function.

All health authorities in B.C. operate ADPs either directly with their own staff or through contracted service providers. The majority of the sites are located within other facilities – usually residential care – to allow for shared support services such as meal provision and housekeeping. With very few exceptions, all ADPs operate on a Monday to Friday office hours basis.

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The Ministry of Health criteria for acceptance into an ADP is very broad and fits a large number of the home care population. Unlike residential care access this criteria does not prioritize based on need or urgency. In practice, ADP managers often determine urgency and base their decision on the number of phone calls and anecdotal evidence of need provided by community case managers and/or stressed families.

This ad hoc approach also applies to waitlists. While there is no reliable data to quantify the waitlist for ADPs, all health authorities report there are waiting lists and this is confirmed by the anecdotal stories of stressed caregivers who want, but cannot access, ADPs.

A more systematic approach based on the principles of triage should be used for assessing access to ADPs, and master waitlists should be maintained in each health authority. This would provide greater clarity and confidence in the access and admissions process.

ADP Eligibility Criteria

- eligible for home and community care services
- unable to function independently because of chronic, health-related problems;
- assessed as requiring an ADP as part of care plan; and
- have agreed to pay the daily rate

"Adult Day Services"
Government of BC website

Most attendees of ADPs require assistance with transportation to reach the program. This is noted by the health authorities as a challenge for most sites. If a site doesn't have its own vehicle to collect attendees – and many do not – then the service is reliant on either HandyDART,

volunteer drivers or other community type buses which can be complicated to organize and is often cited as a reason for low attendance. This might help explain in part why 25% of available days of ADPs were unfilled in 2013/14.

Currently only 7% of assessed seniors participated in an ADP in the last seven days. This is significantly less than the 54% identified

Of the 6,206 people attending ADPs in B.C. in 2013/14:

- 59% attend 1 day/week
- 37% 2-3 days
- 4% >3 days

as people who could benefit from ADPs. When we look at the target population of clients most in need of an ADP we find

the participation rate rises slightly to 8%. More significantly, only 9% of those clients whose caregivers indicate distress participated in an ADP, leaving 91% of distressed caregivers not accessing ADPs.

In addition to the target population of clients who would benefit from ADPs, a review of data from the Ministry of Health showed the capacity in ADPs has not kept pace with the



growth of the aging population.

From 2011 to 2014, growth in the B.C. population aged 75 and over was 12%. The actual number of ADP clients during this time decreased 5%, and the actual days utilized dropped 3%. This indicates that in real terms

From 2011/12 to 2013/14:

- number of ADP clients has decreased 5%
- number of ADP days utilized has decreased 3%
- population 75+ increased 12%

the number of ADP clients has decreased 20%, and the number of days utilized has decreased 18% in the last three years.

Days utilized refers to the number of times an available day has a client in attendance.

For example, an ADP with the capacity to host 30 people at

a time that operates for 248 days a year has 7,440 ADP days available. If this same ADP were to open on Saturday they would have 9,000 ADP days available, if they were to extend their hours and offer two shifts of ADPs per day they would have double the number of days available and so forth.

Surprisingly, the data also reveal that in 2013/14, 25% of ADP spaces were unfilled, despite the fact that there were reported waiting lists. The variation in the vacancy rate ranges from a low of 7% in Fraser Health to a high of 44% in Northern Health. There are no data that explain the reason(s) for this unused capacity in ADPs.

A key aspect of the ADP is the degree to which the relief is meaningful. We know that the single biggest contribution to caregiver distress is the number of care hours provided by the unpaid caregiver. These are logically reduced when the client is attending an adult day program for up to seven hours of the day.

ADP Client Counts

HA*	2011/12	2012/13	2013/14
NHA	437	405	408
IHA	1,896	1,802	1,787
FHA	1,700	1,550	1,473
VCH	1,242	1,319	1,252
VIHA	1,278	1,100	1,293
B.C.**	6,540	6,163	6,206

ADP Days Utilized

	2011/12	2012/13	2013/14
NHA	19,756	18,185	19,651
IHA	71,080	66,710	67,593
FHA	63,775	62,453	62,033
VCH	56,723	62,208	57,537
VIHA	47,719	41,604	45,513
B.C.	259,053	251,160	252,327

ADP Vacancy

	2012/13 % Unused	2013/14 % Unused
NHA	48%	44%
IHA	30%	27%
FHA	6%	7%
VCH	25%	30%
VIHA	32%	25%
B.C.	26%	25%

*The Health Authorities (HAs) are Northern (NHA), Interior (IHA), Fraser (FHA), Vancouver Coastal (VCHA), and Vancouver Island (VIHA).

**Clients are counted uniquely at each HA level and at B.C. level. Clients receiving service from more than one HA contribute one count to each HA, but are only counted once at the B.C. level, therefore, HA counts do not sum to the B.C. totals.

Data Source: 2014-1126 HCC Annual Client Counts Volumes Rates 2013-14 (October 30, 2014.)

In examining the B.C. data, we found that B.C.'s ADPs provided 41 days per year per client. This is contrasted to Alberta, for example, where

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clients enjoy more than double the amount of ADP days with an average of 103 days per client per year. It should also be noted that caregiver distress in Alberta is 45% less than in B.C.

The degree to which the higher utilization of those enrolled in ADPs has driven the 45% lower rate of caregiver distress in Alberta is more difficult to quantify. It is likely one of many factors, including lower client complexity as well as higher utilization of home support, which we reference later in this report.

An examination of the data revealed another benefit of certain types of ADPs, namely a reduction in visits to the Emergency Department (ED) and a reduction of in-patient admissions (IPA) to hospital for clients enrolled in the program.

Alberta has produced stunning results with its Comprehensive Adult Day Programs (C3 and CHOICE). These are advanced ADPs focused on the most frail and complex clients. Physicians, pharmacists, therapists and nurses are all part of the on-site team that assess and treat clients attending the ADP. This level of ADP is not currently offered in B.C.

Examining ED visits and IPA to hospital for the six months pre and post enrollment in the ADP, it was found that clients of the CHOICE/C3 ADPs experienced a 34% reduction in ED visits and a 49% reduction in IPA to hospital in the first six months of enrollment in the ADP.

The impact of these results on caregiver distress is difficult to quantify, however common sense would conclude that reducing trips to the ED and unscheduled hospital admissions would reduce the distress to caregivers as well as improve quality of life for the client. There is also a savings to the healthcare system.

The success of the Alberta program is linked to a higher level of ADP with significant professional and clinical supports and ensuring participants attend at least three days per week. While Alberta also provides the basic

High intensity ADPs:

- reduced emergency visits by 34%
- reduced hospital admissions by 49%

level ADP we find here in B.C., the Alberta model recognizes the limitations of this “one size fits all” approach to ADPs.

For example, we examined the

profile of 2,218 people attending ADPs in 2012/13. It showed 66% to be at a high risk of requiring residential care and 55% with dementia. However, it also means that 34% were not at risk of requiring residential care, and 45% did not have a diagnosis of dementia. Trying to serve these two very different client groups could result in a program that does not fully meet the needs of either.

Through creating two different models of ADPs, Alberta has managed to create a higher intensity ADP to focus on clients with complex needs. This higher intensity support with access to physicians, nurse practitioners and rehabilitation professionals in conjunction with the social aspects of a traditional day program can significantly improve overall health and reduce use of acute care resources.

Our review of ADPs in B.C. provides sufficient evidence to suggest that B.C. needs to deliver ADPs to an increased number of clients, and increase the number of days per week clients are able to attend an ADP. Part of this can be achieved by increasing the utilization of existing spaces.

The evidence would also support a re-examination of the basic model of ADPs in B.C.

Offering different levels of care by creating some ADPs that focus on more complex clients will both relieve caregiver distress and offer system savings through reduced emergency room utilization and in-patient admissions to hospital. This savings added to cost savings from residential care diversions will help to fund any net new spaces that are required.

In addition to increasing utilization and creating a higher level of ADP, the lack of standardization and reporting needs to be addressed. This applies to admission criteria, client charges and waitlists both between health authorities and within health authorities. How you are assessed and what you pay should be the same regardless of where you live in B.C. Ability to pay should be a factor in considering day program fees and no one should be denied access due to finances.

In-Home Respite

In-home respite is provided through paid community health workers under the home support program. For this report we have looked at home support from the perspective of the respite it provides for caregivers. This is not a review of the home support program per se. The Office of the Seniors Advocate is currently reviewing the overall home support program and will be reporting the findings in early 2016.

Respite through the home support program can take two forms. There is the respite from caregiving duties that occurs with home support visits that perform specific tasks. This can include getting the client up in the morning, washed and dressed, performing delegated nursing tasks such as putting in eyedrops, changing compression stockings or assisting with other medications, to name a few. This type of home support is generally

delivered in blocks of time of an hour or less and there can be several visits in a day.



The other form of respite is provided for those clients who cannot be left alone. In this form of respite, which would be called a “respite shift” the community health worker would stay with the client for three or more hours. The purpose of these shifts is to allow the unpaid caregiver time to run errands, take a nap or engage in whatever activity will bring them relief.

Eligibility for home support and the amount of home support provided is determined by the case manager using the RAI-HC. The case manager will look at all resources available to support the senior, including contributions of family caregivers, to determine the amount of authorized home support hours. The underlying policy of the program assumes an obligation on the part of family caregivers to provide as much of the care as possible with home support filling the gap between what the client needs and what the family can provide. The challenge with this underlying premise is the difference of opinion that might exist amongst case managers as to what is reasonable for family members to assume in terms of care

**For age 75+
the growth
in home
support trails
population
growth by 7%**

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obligations. There is also the issue of changing circumstances and health status for those family members who are providing care.

There is no mandated maximum or minimum number of home support hours a client can receive. However, for the past several years a common practice has seen clients receive up to 120 hours a month, or four hours a day, before they are referred to residential care. Anecdotal reports would indicate an inconsistency in the application of this practice. Lack of staffing or budget constraints rather than client need would appear to influence the hours of support provided in some parts of the province.

There are two categories of task a CHW can perform: Assignable and Delegated. Assignable tasks include a wide range of personal assistance items that the worker has been trained to do, are within the scope of that training and which the worker can perform without any guidance from a regulated health professional. Delegated tasks are those that

CHWs assist clients with:

- Personal Care, Bathing and Toileting
- Dressing
- Eating
- Meal Preparation
- Laundry
- Lifts and Transfers
- Catheter Care
- Breathing and Coughing Exercises
- Diabetic Management
- Medication Management
- Skin and Wound Care
- Mobilization/Activity/ Exercises
- Tube Feedings
- First Aid

would normally be done by a regulated health professional (for example a nurse or therapist) and which require additional training and oversight of the CHW. The important factors that need to be present are that the client or a family member cannot perform the task themselves,

the professional is comfortable that the CHW is competent to perform the task and the professional can offer adequate oversight of the worker. A typical delegated task is assistance to take medications, where the client has a physical or cognitive disability preventing them from doing this task.

CHWs are required to follow and cannot deviate from the assigned care plan – while they can independently perform these tasks they cannot make decisions as to whether a task can be eliminated or added to the care plan. This can result in frustration for both the client and the CHW.

The first challenge encountered in gathering data to assess the adequacy of home support as respite is the lack of coding to distinguish which hours of home support are offered as a “respite shift”. This left us unable to determine how many seniors are benefitting from the type of respite home support can provide to those caregivers who live with someone who cannot be left alone. We know the scheduling software used is capable of capturing this data if the shift is entered as “respite”. The OSA will be asking each health authority to begin coding home support respite shifts going forward.

There was sufficient data, however, for us to examine the efficacy of home support as respite from actual caregiving tasks.

The first level of analysis was to examine whether the home support program in terms of the number of clients served and the hours delivered is keeping pace with the growth in the aging population.

The data indicate that in nominal terms both the number of clients receiving care and the hours of care they are receiving has increased. However, when we factor in the growth of the

population aged 65 and over, we find that in relative terms there has been a decrease in the number of clients and the number of home support hours.

From 2005/06 to 2013/14, although the number of home support clients and number of home support hours have increased, these increases have not kept up with the growth in the aging population. For those aged 65 and over, the gap is 4%, and for those aged 75 and over the gap is 7% (home support client rates per 1,000 aged 65+ and 75+). This would appear to validate anecdotal stories from seniors and their caregivers who are frustrated by the inability to get sufficient home support.

Home Support Rate per 1,000, 75+

	2005/06	2013/14	% Change
NHA	103.2	70.7	-31%
IHA	98.3	81.7	-17%
FHA	72.7	75.6	4%
VCH	72.8	66.8	-8%
VIHA	87.4	79.4	-9%
B.C.	81.1	75.1	-7%

The next level of data examined was the RAI-HC which reports on those seniors who have been assessed and enrolled in the home support program.

As previously referenced in this report, evidence supports a strong correlation between caregiver distress and the number of hours of care being provided by the caregiver. We can lower caregiver distress by substituting the care provided by the unpaid caregiver with care provided by a CHW.

For these reasons, we were very surprised to learn that only 53% of seniors who were enrolled in the home support program

reported receiving home support in the last seven days. Some of this can be explained by first time assessments, returns from hospital, or low care needs. Taking all those factors into account, however, there is still a high number of seniors not receiving service in the last seven days.

47% of seniors enrolled in the home support program received no home support in the last 7 days

This number does not change much when we look at the highest need clients. Pooling those clients who score MAPLe 4/5 showed an actual decrease to 49% receiving home support in the last seven days. At this level of assessment it would be expected that a person would require daily care, and perhaps many times per day, yet over half did not receive any home support in the previous week. Significantly, when we examined those clients who indicate caregiver distress there is a further decrease, with only 47% reporting home support in the last seven days.

When we compared B.C. to Alberta's home support eligible clients, we found some notable differences. In B.C.:

- a higher percentage of caregivers reported distress (B.C. 29%; Alberta 14%);
- a lower percentage of clients received home support services in the last 7 days (B.C. 53%; Alberta 65%); and
- the complexity of client needs was higher (B.C. 53%; Alberta 37%).

In summary, clients in B.C. have higher needs and more caregiver distress, but received less home support than their counterparts in Alberta.

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B.C. Alberta Comparison

	B.C. Home Support Clients (n=31,084)	Alberta Home Support Clients (n=23,271)
Caregiver Distress	29%	14%
MAPLe (4/5)	53%	37%
Home support in last 7 days	53%	65%

The evidence supports that clients enrolled in the home support program do not appear to be receiving sufficient hours of home support, and lower home support utilization links to higher caregiver distress.

As a first step in addressing this, all health authorities should closely monitor those clients whose caregivers are indicating distress in the RAI-HC assessment. All efforts should be made to ensure these caregivers get the necessary home support hours as we know that supporting unpaid caregivers will divert admissions to residential care.

In addition to those who are enrolled in the home support program, but not getting sufficient service, there is also the question of those seniors who might benefit from home support services but are not even enrolled. This question is raised by the data indicating that home support has not kept pace with the potential demand from an increasingly aging population. This issue is not addressed directly in this report but will be part of a dedicated report on home support currently being researched by the Office of the Seniors Advocate.

Respite Beds

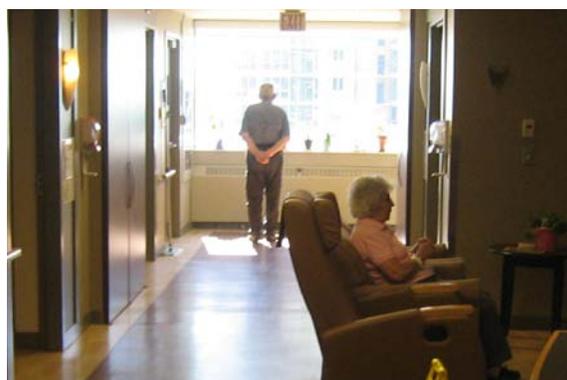
There are times where caregivers need a longer break from the person for whom they are caring. These reasons can range from

profound exhaustion to accommodating a convalescence by the primary caregiver or, in the case of sons and daughters who are caregivers, time to leave town to get a real break from their parent(s) and from their regular job. It is these situations that respite beds, usually located in residential care facilities are meant to remedy.

As we sought to determine the efficacy of the respite bed program in B.C. we found a lack of standardization both between and within health authorities. Varying definitions of whether or not a bed was referred to as respite, a lack of effective waitlists, little or no triaging of referrals make it impossible to provide definitive statements of the current state of respite beds in B.C. What we are left with is an hypothesis based on:

- data showing who might qualify
- growth in population;
- anecdotal stories of distressed caregivers measured against the current state of bed numbers and utilization.

As stated previously in this report, growth in the population aged 75 and over from 2012 to 2015 was 12%. We can measure this against the increase/decrease in respite beds along with the numbers from the RAI-HC showing, in absolute terms the potential population that could benefit from a respite bed.



We can find data to tell us, on a given day in B.C., how many beds are designated as “respite.” The challenge is that this number could increase or decrease the following week given the current practice of “floating” respite beds. This practice means that a facility may designate three of its beds as respite, however if there is pressure for a permanent placement into residential care, then the respite bed will be taken out of circulation and used for a permanent placement.

Looking over the past four years, we can determine that on the day of the “snapshot in time” the number of beds ranged from a high of 227 in 2012 to a low of 198 in 2014 and most recently was pegged at 200 in 2015. This would indicate that on one level of measurement there has been a decrease in the number of actual respite beds over the past four years of 12%.

Number of Respite Beds Available March 31st, 2012-2015 (Excluding Palliative Beds):

	2012	2013	2014	2015
NHA	33	31	32	34
IHA	70	64	60	61
FHA	58	57	43	41
VCH	25	25	24	25
VIHA	41	41	39	39
B.C.	227	218	198	200

Data Source: HA Reported Bed Numbers (Rpt 03-Facilities Report Detained Mar 2012; Mar 2013, Sept 2014 and Mar 2015). Note: 308 additional palliative beds province wide not included.

The number of beds, however, should be viewed within the context of utilization. This can be measured by:

- number of clients;
- number of admissions;
- average length of stay

The 2012/13 to 2014/15 data we examined showed a:

- 12% increase in actual clients;
- 10% increase in actual admissions; and
- reduction in average length of stay in most health authorities.

The potential to meet the demand however varied greatly across health authorities as illustrated in the chart below. While the low numbers in Northern Health would be expected given their smaller population, the Vancouver Coastal rate was surprisingly low relative to the other health authorities.

Number of Discrete Clients Utilizing Residential Care Respite

	2012/13	2013/14	2014/15
NHA	248	246	234
IHA	1,119	1,284	1,418
FHA	1,081	1,113	1,168
VCH	262	289	275
VIHA	674	646	700
B.C.	3,384	3,578	3,795

Total Number of Residential Respite Admissions

	2012/13	2013/14	2014/15
NHA	340	378	350
IHA	1,541	1,764	1,831
FHA	1,696	1,764	1,816
VCH	409	454	501
VIHA	1,193	1,177	1,267
B.C.	5,179	5,537	5,765

Data source: HA reported admissions, June 2015.

Similar to ADPs, the effectiveness of a respite bed as relief for the caregiver is linked to the length of time the caregiver is relieved. For this reason, we were surprised to see the data show a reduction in average length of stay. While a larger number of clients have been

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served, they are staying for shorter periods of time. However, perhaps more startling is the difference in average length of stay between health authorities, for example a low of 9 days in Island Health (VIHA) to a high of 27 days for Fraser Health (FHA) in 2014/15. This data supports more people and more admissions but fewer beds.

Average Length of Stay for Residential Care Respite (Days per stay per person)

	2012/13	2013/14	2014/15
NHA	18.1	16.7	14.6
IHA	16.3	16.5	16.5
FHA	28.7	28.4	26.9
VCH	22.5	21.1	21.0
VIHA	9.6	9.5	9.0

The backdrop against which all these numbers should be viewed is the potential population that could benefit from a respite bed.

Using the RAI-HC, we estimate a total potential pool of over 15,000 seniors who could benefit from respite, yet just over 3,700 used a respite bed in 2014/15. Even allowing for the complications of a respite bed that will not make it as appropriate as an ADP or home support as a respite service, there is still a significant gap. This combines with the anecdotal stories of unmet need that lead us to the conclusion there is an insufficient supply of respite beds in B.C.

However, we believe that increasing the number of respite beds must be viewed within the context of changing the current model of how respite beds are operated.

As stated, the current model places the overwhelming majority of respite beds within residential care facilities where they might account for 5% or less of the total beds. In practical terms this means a facility that is

geared toward providing a long term home for over 95% of its residents must find a way to accommodate sometimes only one or two residents, who are there for a short time of a month or less. Combine this with the “floating bed” system where pressure for the bed to be assigned to a permanent residential care client results in a loss of a respite bed in that facility and you arguably have a recipe for a fragmented approach to respite care beds that does not best serve the needs of the client or the facility operators.

The model of dedicated respite care facilities, of which there are a few in the province, holds promise of a better outcome for clients and their stressed caregivers. Dedicated respite facilities, or dedicated units within a facility, can develop programs that recognize the transitory nature of respite. Assessment, treatment, and therapies geared to clients who primarily live independently in the community can be more effectively administered if there is a group of 10 or more respite clients.

Health leaders in all health authorities told us that opportunities existed for not only more respite bed care but enhancements such as rehabilitation support for the senior when they use such beds to enhance their level of independence when they return



home. Currently, when respite clients are in the respite bed they receive very little special attention and yet this could be a major opportunity for these seniors to receive rehabilitation and clinical care supports to solve problems in the home that may be contributing to the risk for residential care. Three good examples might be falls prevention interventions, targeted exercise programs and medication reassessment to minimize the risks associated with overmedication when the client returns home. In other words, respite care could become a key element in

the continuum of care to keep people at home by offering clinical assessment, treatment and therapy that is difficult to deliver into the clients home in a more appropriate and cost effective manner.

Dedicated respite facilities or units with an appropriate critical mass can also go toward reducing the frustration of operators. They argue respite beds require more work to maintain both administratively and clinically given the turnover.

Summary

Unpaid caregivers in B.C., most of whom are family members, need more support. We need to achieve a system shift in our thinking and view supporting unpaid caregivers as an investment in the healthcare system.

We need to begin with our most vulnerable unpaid caregivers, the 9,000 men and women who are in distress and who are caring for their mom, dad, husband or wife. Through examining the data we found that we are failing to connect these distressed caregivers with the respite services they have been assessed as eligible for.

We must focus on improving access across the respite spectrum. We must also ensure there are standard assessments for who gets what service, when, and how much they pay, regardless of where they live in B.C. Measuring

our success in achieving this will require knowing how many people are waiting and for how long, and this measurement needs to be the same in all health authorities.

When we look to the future, we can measure our success, in part, if we see that clients who have a distressed caregiver are using more adult day programs, home support, and respite beds. This will not eradicate caregiver distress, but it will help address the primary trigger of caregiver distress by reducing the hours of care provided by the unpaid caregiver. Working collaboratively, we are confident that system improvements can be made that will ensure caregivers get the respite they need, and as a result, seniors get the highest quality care possible while living as independently as possible.

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