Caregivers in Distress

A Growing Problem

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Among the myriad of issues associated with aging, the question of how best to care for seniors if they require help can be one of the most complex, confusing and exhausting areas to address. For many seniors, care inevitably rests on the shoulders of spouses, children, friends, or neighbours. The care provided is typically unpaid, largely unrecognized by society, and often under-appreciated. Increasingly, as our population ages, the question is not if someone will be faced with the reality of caring for an elderly loved one, but when.

The care that over one million unpaid caregivers in British Columbia provide each day varies greatly. It may be a simple ride to the grocery store or it could be full 24-hour live-in help. Many caregivers view these tasks as a privilege, others a duty, and some a burden. As I travel the province, hearing the stories of seniors and their families, I continue to be humbled by the commitment of this network of care that is a critical pillar in the stability of our health care system.

The personal stories, when combined with the available data about caregivers and those for whom they care, paints a vivid picture of a system under stress. This is similar to the picture that emerged in our 2015 report *Caregivers in Distress: More Respite Needed*.

When we examined levels of caregiver distress **in 2015**, we found that **29% of caregivers were experiencing distress** (defined as feeling distressed, angry or depressed) or were not able to continue in caring activities. **Two years later**, when we looked at the most current data, we saw that **this number had actually risen from 29% to 31%**. This trend is disturbing on its own, but when we also looked at the supports available to unpaid caregivers, such as adult day programs, respite and home support, we saw that they are increasingly not keeping pace with the aging population and that on the whole are less accessible than we reported in 2015. All of this is compounded by the documented increasing complexity of care needs within the home support population over the past two years.

This report demonstrates that we can be doing more to support unpaid caregivers. There are many steps that we need to take to address the growing trend of caregiver distress. The recommendations identified in this report offer a focused starting point for the critical work that lies ahead.

On behalf of my office and the continuing work that we conduct, I would like to thank all those who provided data and assisted with the development of this report. Most importantly, I want to personally thank all the wives, husbands, sons, daughters, assorted other family members and friends and neighbours who are caring for a loved one. Your sacrifices are acknowledged and appreciated; I am confident there is a commitment to supporting you as a caregiver, and I hope you can find more relief in the future.

Sincerely

Isobel Mackenzie
Seniors Advocate
Province of British Columbia

Context

As we age, many of us may need assistance to remain living at home independently. It may be that we need a ride to the grocery store or a medical appointment. Sometimes, our need for help may progress to needing assistance with everyday activities, such as bathing, toileting and medication management – activities collectively referred to as Activities of Daily Living (ADLs). For many British Columbians, most care – of any kind – is not provided by paid caregivers, but rather by family, neighbours, or friends.

Statistics Canada estimates there are approximately one million unpaid caregivers in the province. According to the Health Council of Canada, unpaid caregivers provide roughly three-quarters of care for people receiving care at home in Canada. Replacing this care with paid caregivers would cost over $25 billion per year in Canada, or $3.5 billion in British Columbia.[1] The work of caregivers can feel undervalued and at times invisible, but there is no question that the work they provide every day, in every corner of the province, is a critical pillar in our health care system, allowing seniors to remain at home and delay – or even prevent – costly care options, such as subsidized residential care or hospital stays.

This report examines one subset of caregivers in the province – those who provide care and assistance to clients who are also receiving publicly subsidized home support. The home support program, delivered through B.C.'s five regional health authorities, provides clients with assistance in activities such as bathing, dressing, toileting, and managing medications. The home support program is explicitly defined as operating to *supplement* the care provided by an informal caregiver.

The goal of the home support program is to assist seniors to live as independently as possible in their own homes for as long as possible. Achieving this goal is not only a good outcome from the perspective of person-centred care, but also a financially desirable outcome. Seniors who are not able to live independently at home will overwhelmingly reside in one of B.C.'s 28,000 publicly funded residential care beds at a much higher cost than living at home with support.

Unpaid caregivers, who are predominantly family members, are a crucial component in the success of home support to enable independence. For this reason, the Office of the Seniors Advocate (OSA) believes that meeting the needs of caregivers should be seen as a way of meeting the needs of the client and that policy should be designed to support this outcome.

To determine if this outcome is being achieved, the OSA looked at the most comparable, objective and robust data available on stress levels of unpaid caregivers for the 30,000-plus clients receiving home support services. While this report specifically focuses on caregivers

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[1] Proportional calculation based on number of seniors in British Columbia relative to Canada as a whole.

who care for clients receiving home support services, it is important to understand there are many more seniors with complex care needs who are receiving their ADL support either exclusively from their family caregiver, from a privately-financed caregiver, or a combination of both. This is supported by Ministry of Health data showing that, in 2015/16, approximately 140,000 seniors with highly complex chronic conditions did not receive any publicly subsidized home support or long term care. For example, this may be an 81-year-old woman with osteoarthritis, hypertension, and diabetes who is widowed, living alone, and is looked in on by her adult daughter who brings meals and picks up medications. While detailed data on how these seniors are having their care needs met are not available, it is clear there are many more British Columbians providing care to a greater number of seniors than we have captured in this report. This emphasizes the need for ensuring broad access to caregiver supports.

This report

This report updates data and analysis highlighted in the OSA's 2015 report, *Caregivers in Distress: More Respite Needed*.

The prior report was the first time province-wide data were examined to look at caregivers using InterRAI's Residential Assessment Instrument – Home Care (RAI-HC) tool that measures, among other things, the level of caregiver distress amongst home support clients[2]. In our 2015 report, we found:

- 94% of clients reported having an unpaid caregiver
- 29% of caregivers providing care to home support clients were in distress
- 12% used adult day programs
- No tracking of respite hours offered through the home support program
- No consistent policy on the authorization of respite home support hours
- Declining overall hours of home support
- 11% used a residential care respite bed in the past year
- No consistent tracking within or between health authorities on the number of residential care respite beds
- No consistent wait list developed within most health authorities for access to residential care respite

By highlighting the issues and putting concrete numbers to the utilization of caregiver supports, we hoped that we would see some improvement as indicated by: lower levels of caregiver distress; increased utilization of supports; or, ideally, both.

This report, like the 2015 report, uses RAI-HC clinical assessment data along with service data from the Ministry of Health's Home and Community Care Minimum Reporting Requirements database[3]. Together, these data provide a picture of what types of service are received by the client along with their medical and functional characteristics, as well as the amount of care being provided by family and friends acting as caregivers. Through this, we can better understand the factors that influence caregiver distress and we can more confidently compare year to year results to see if we are improving.

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[2] Our 2015 reported used 2012/13 RAI-HC data

[3] Unless otherwise noted, all data in this report is sourced from RAI-HC assessments in the Ministry of Health's Home Care Reporting System (HCRS) database and Minimum Reporting Requirements database.

Who is being cared for and how have they changed?

Within the home support system, clients demonstrate a wide variety of care needs and challenges. While all clients share the common characteristic of being assessed as needing additional support to be able to safely remain living at home, the factors contributing to this need are as diverse as the clients themselves. It is intuitive to associate increasingly intense care needs with increasing demands on an informal caregiver. Some of this will be due to a higher workload for the caregiver, but some may also be due to the complexity, and attendant responsibility, of the care that must be delivered.

To understand the complexity of a client's needs, we consider three key measures that arise from RAI-HC data: the Activities of Daily Living (ADL) scale, the Cognitive Performance Scale (CPS), and the Method for Assigning Priority Levels (MAPLe) score.

- The ADL scale assesses a client's ability to perform fundamental activities needed for independence, such as getting out of bed, getting to the bathroom, dressing, and personal care.
- The CPS assesses a client's cognitive functioning along the lines of short term memory, decision making, and ability to communicate.
- The MAPLe score is considered a proxy for risk or probability of admission to residential care. The MAPLe algorithm takes into account elements such as the difficulty of delivering care to the client (such as presence of aggressive

RAI-HC Measurement Scales

For both the ADL scale and CPS, we have chosen a score of 3 or higher as the threshold indicating higher complexity of needs.

For the **ADL scale**, 3 corresponds to a person needing limited assistance with at least one of: personal hygiene, moving about in the home, toileting, and/or eating. A higher score on the scale will indicate increased assistance for at least one of these activities.

For the **CPS**, 3 corresponds to a person having moderate cognitive impairment. At minimum, a person will have difficulties in two of the following areas: cognitive skills for daily decision-making, making oneself understood, and short-term memory with severe impairment in either daily decision making or making oneself understood. A higher score on the CPS indicates a greater number of severely impaired areas.

For the **MAPLe score**, we have chosen a score of 4 as the threshold indicating higher complexity of needs. This corresponds to a risk of "high" for admission to residential care. This is in line with other research, such as the Canadian Institute for Health Information's recent report[1] *Seniors in Transition* that looked at potentially inappropriate admissions to residential care. In that report, a MAPLe score of 4 or higher was used as one potential indicator of a client's "appropriate" placement into residential care.

behaviours), suitability of home environment, and medical concerns that may signal the need for around-the-clock supervision, such as wandering, swallowing issues, and risk for falls.

Both ADL and CPS are measured on a seven point scale (0-6), with higher numbers indicating lower levels of functioning and an attendant increase in care needs. The MAPLe score is given on a five point scale (1-5), with higher numbers indicating a greater risk for admission to residential care. It is generally accepted that a MAPLe score of 4 or 5 indicates placement in a care facility could be appropriate.

The table below shows that, no matter what measure of complexity of care needs is used, the complexity of care needs of clients in the home support program has increased between 2013/14 and 2015/16.

Changes in clinical characteristics between 2013/14 and 2015/16

	2013/14	2015/16	Change 13/14 -> 15/16
ADL 3+	19%	20%	↑ 7%
CPS 3+	20%	21%	↑ 7%
Depression Rating Scale 3+	20%	21%	↑ 4%
MAPLe 4+	50%	52%	↑ 4%
CHESS[4] 2+	39%	40%	↑ 2%
Dementia	31%	32%	↑ 4%
Aggressive behaviour	11%	12%	↑ 7%
IADL[5]: Medication management difficulty	69%	72%	↑ 4%

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[4] Changes in Health, End Stage Disease and Symptoms and Signs (CHESS) scale. A measure of medical stability.

[5] Instrumental Activities of Daily Living (IADL) includes activities central, but not necessarily fundamental, to maintaining independence, such as shopping, managing one's finances, and housework.

Who are the caregivers?

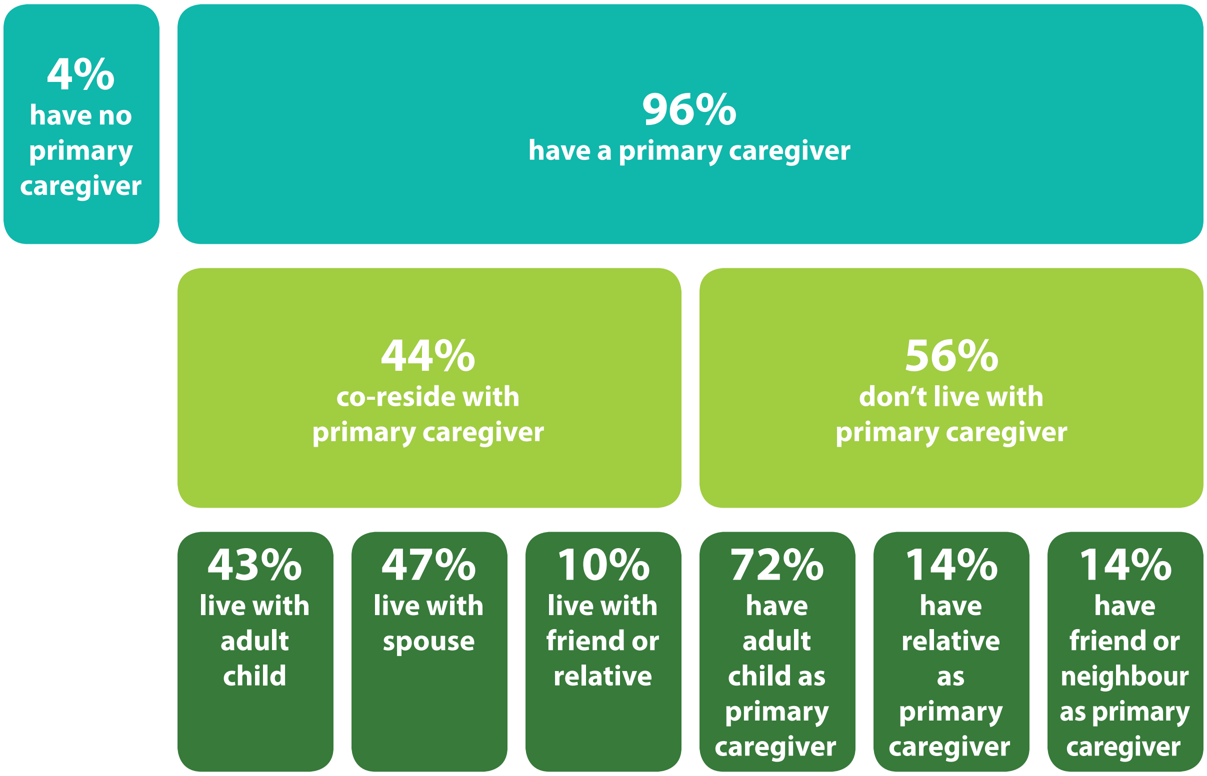
Typically, informal caregivers are differentiated from formal caregivers. An "informal" caregiver is a person who provides unpaid (informal) care to the client. This is in contrast to a formal caregiver, who would be a paid, professional caregiver, such as a care aide or nurse. Typically, the informal caregiver is a family member, although in some cases it can be a client's neighbour or friend. This report uses the terms informal caregiver, unpaid caregiver and family caregiver interchangeably. Although many home support clients will have a network of support from various family members, we focus on the caregiver directly identified as being the primary caregiver in the RAI-HC assessment.

We identified 26,310 primary caregivers providing care in 2015/16[6]; 91% of these primary caregivers were family members.

- 58% were adult children
- 21% were a spouse
- 12% were other family members

The chart below provides a breakdown of the caregiving arrangements in terms of whether the client and caregiver co-reside and their relationship.

Breakdown: who are the caregivers and where are they living?



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[6] In 2015/16.

Clear patterns emerge when looking at the characteristics of clients in conjunction with their relationship to their caregivers. For example:

- When the caregiver is a spouse, the client's average age is 79.6
- When the caregiver is an adult child, the client's average age is 86.4
- Overall, 64% of home support clients are female, but:
    - When the caregiver is an adult child, the majority of clients (78%) are female
    - When the caregiver is a spouse, the majority of clients (58%) are male
- There is no age difference by gender among clients cared for by an adult child, with both male and female clients being, on average, 86.4 years old
- Among clients cared for by a spouse, female clients are 77.8 years old on average compared to 80.9 years old for males

These data are consistent with the pattern of increased life expectancy for females. They suggest that, to a large extent, spouses will care for one another, but once a senior loses a spouse, the adult child or children will step in to provide care for the remaining parent, who is more likely to be the mother. Overall, home support clients are less likely to be married (29%) compared to the overall population age 65 and over (58%), suggesting that death of a partner may be one of the triggers for accessing home support and the need for caregiver support.

How are caregivers coping?

We can determine how caregivers are coping by looking at RAI-HC assessment data, which assesses how caregivers are coping with their role and documents the hours of care they are providing. Caregiver distress is identified by looking at responses to: 1) whether the caregiver feels they are unable to continue in their caregiver duties and 2) whether the caregiver is expressing feelings of distress, anger, or depression. In conjunction with this, caregivers are asked about the specific amount of time spent on care duties involving ADLs such as bathing, feeding, toileting and dressing.

With these assessment data[7], we are able to determine how many caregivers are in distress and how many hours of care they are providing. When we link assessment data with the services each client receives, we find that, **in 2015/16, 31% of clients have a primary caregiver in distress**. This is a **7% increase** over what we found in the 2015 report *Caregivers in Distress: More Respite Needed*[8]. Not only is the rate of distress higher, but there are more clients and caregivers now. Over this period, **the actual number of primary caregivers identifying as distressed increased by over 1,000**, which represents a **14% increase** in the actual number of caregivers in distress.

In addition to the two questions asked as part of the RAI-HC assessment, three health authorities have indicated that they use additional caregiver distress assessment tools to better understand the extent to which caregivers experience distress and their specific stressors. In all cases, these tools are used at the discretion of health professionals. Two health authorities indicated that they do not use any additional tools to assess caregiver distress but rely exclusively on the RAI-HC assessment and clinical judgement.

Across the health authorities that use additional caregiver assessment tools, five different tools are used with no standardization or consistency across the health authorities. In addition, there are no systems in place to capture and report on more detailed assessment data that may help inform our understanding of caregiver distress across the province.

Using additional tools to examine caregiver issues is a laudable goal and health authorities are to be congratulated for recognizing this need. However, the inconsistent and fragmented approach to gathering additional data makes it impossible to get a more in-depth picture of caregiver distress at a provincial level.

What causes distress?

The nature of a caregiving arrangement (relationship, co-residing status), the complexity of care needs, and the amount of care delivered by the informal caregiver all impact caregivers and their levels of distress. We have analyzed these various factors to better understand the impact they have on the rate of caregivers identifying as distressed.

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[7] From 2015/16 RAI-HC assessments.

[8] From 2012/13 RAI-HC assessments.

Some of our overall findings indicate:

Client factors:

- Mild cognitive impairment approximately doubles the risk of caregiver distress, while moderate to severe impairment triples the risk
- Mild IADL impairment increases the risk of caregiver distress by two-thirds, while moderate to severe impairment almost triples the risk
- The level of a client's depression, measured as 3 or higher on the 15 point Depression Rating Scale, is associated with more than double the risk of caregiver distress; a score of 3 or higher may be indicative of a problem with depression
- Caring for a client with dementia is associated with a 25% increased risk of caregiver distress
- The presence of any behavioural and psychological symptoms of dementia (BPSD) is associated with a 75% increased risk of caregiver distress

Caregiver factors:

- A co-residing caregiver who is not a spouse is associated with a 40% increased risk of distress, while being a spouse is associated with an 80% increased risk; both estimates are relative to a non-co-residing caregiver (any relation)
- Higher levels of informal care hours are associated with a mild increase in risk of caregiver distress, which suggests that, all else being equal, a caregiver's provision of more hours of care is, in and of itself, a risk factor for caregiver distress

Perspective from Family Caregivers of BC

The Family Caregivers of BC is a non-profit organization that supports caregivers. One of its services is a Caregiver Support Line, which provides support and advice to informal caregivers, and also connects them with other resources that may be available. As part of the Caregiver Support Line, Family Caregivers of BC also provides one-on-one Caregiver Consults to provide more complex, in-depth support for problem solving and planning.

Five frequent areas of concern

- Navigating the system: how to access and understand services (home support, respite, assisted living, residential care); how to find private home support; panic after hospital discharge; what to do when existing public services are not enough or not working well
- Caregiver burnout: stress, "end of my rope", frustration, anger, helplessness, worry about care recipient, worry about own health
- Financial assistance: where to find it?
- Legal issues: Advanced care planning, Powers of Attorney, substitute decision maker issues
- Need for mental health supports

Distress varies by caregiving arrangement

The relationship between the client and caregiver has an influence on feelings of distress. Analysis shows that when the primary caregiver **co-resides** with the client:

- Overall, 42% of caregivers express distress
  - Where the caregiver is a spouse, 48% express distress
  - Where the caregiver is an adult child, 38% express distress

When the caregiver does **not co-reside** with the client:

- Overall, 24% of caregivers express distress
  - Where the caregiver is an adult child, 26% express distress
  - Where the caregiver is another relative, 22% express distress
  - Where the caregiver is a friend/ neighbour, 15% express distress

The higher rates of distress for co-residing spouses is likely attributed to the age of the caregiver and the impact the increased need for caregiving has on their own physical and psychological health. Higher rates of distress when a caregiver co-resides, regardless of relationship status, is likely due to the higher level of complexity in clients and also the inability of the caregiver to enjoy as much independence from the person they are caring for.

Distress varies by complexity of care needs

The amount of care a person requires is associated with the complexity of their care needs. The tables below show a pattern of increased caregiver distress being associated with increased complexity of care. While increased client complexity should also correspond to increased use of home and community services such as home support, adult day programs and respite beds, the data indicate this is not the case, further exacerbating caregiver distress.

Caregiver distress by complexity of care needs

	Distressed caregiver	Informal care (hours per week)
ADL score 3 or higher	45%	33
ADL score 2 or less	27%	17
CPS score 3 or higher	57%	36
CPS score 2 or less	24%	16
MAPLe score 4 or higher	42%	27
MAPLe score 3 or less	21%	15
Dementia	48%	25
No dementia	24%	17

Alternatives to living at home

In the RAI-HC assessment, the client and their caregiver are asked whether they feel the client would "be better off in another living environment." This is generally considered to be a proxy question for whether the client would be better off in a supportive living environment, such as a licensed care facility or assisted living. The results from this question highlight part of the challenge facing not only caregivers, but also health professionals and policy makers who can be caught between what a client wants and feels is best for them, and what their caregiver wants and feels is best.

Overall, 20% of home support clients actually feel they would be better off living somewhere else, while 29% of their caregivers feel they would be better off. The largest difference between the client and the caregiver is seen when comparing clients with a low MAPLe score versus a high MAPLe score. The MAPLe score is considered a proxy for risk or probability of admission to residential care.

Among clients with a MAPLe score of 1 to 3, 16% of clients and 18% of caregivers believe the client would be better off living somewhere else, indicating that clients and caregivers generally have consensus of opinion. However, among clients with a MAPLe score 4 or 5, only 23% of clients believe they would be better off living somewhere else compared to 39% of their caregivers, demonstrating quite divergent opinions.

Believe client would be better off elsewhere

	All	MAPLe 1-3	MAPLe 4-5
Client	20%	16%	23%
Caregiver	29%	18%	39%
% difference between client and caregiver response	9%	2%	16%

Caregiver distress may be exacerbated by the tension created when a caregiver thinks the person they are caring for would be better off living somewhere else, but the person being cared for wishes to remain where they are. What makes this situation difficult is that caregivers who are making the current living situations tolerable for clients may be at their breaking point.

Distress levels for caregivers of CSIL clients

The only factor identified in the data as being associated with a significant **decrease** in risk for **caregiver distress** was a client being in receipt of self-directed care funds.

B.C., like most jurisdictions in Canada, has a program that allows clients to receive money directly from their health authority and to use that money to pay for the care they need. In B.C., the program is called Choices in Supports for Independent Living (CSIL) and it has existed since 1994. Under this program, client care needs are assessed, care hours are determined and funding provided to the client at a rate of $30.39 per hour (current rate). It is generally accepted that CSIL allows clients more flexibility in choosing who will provide their care and when the care will be provided. There are audit and review processes in place to ensure the money is being spent appropriately and the care is delivered. CSIL is not appropriate for all clients as it does require that either the client or someone they nominate such as a spouse or adult child take responsibility for administration of the funds and assume the role of employer for the caregiver(s).

The data indicate that caregivers of clients under the CSIL program have a **50% lower risk of caregiver distress** even though they are caring for someone who, on average, has a higher level of complex care needs than non-CSIL home support clients.

CSIL would appear to be more cost effective to the health care system as the average cost for health authority delivered home support is $44 an hour compared to $30.39 per hour for CSIL. However, while many caregivers may find this option desirable, it is not widely offered as an option and is difficult to access. Furthermore, in some health authorities, assessment standards are inconsistently interpreted and applied when determining the number of hours of care that would be appropriate for the client's needs.

CSIL Program – Choices in Supports for Independent Living

Brenda has been the primary caregiver for her husband, John, for over eight years, and has managed to continue to support him at home as his multiple sclerosis symptoms progressed because of the flexibility of the CSIL program. Brenda gave up full-time professional work and found a part time job in order to have more time for John and his increased care needs. When John began to require a wheelchair, they sold their two-level home and rented an accessible one-level apartment.

"CSIL has been an excellent fit for us. We choose the caregivers who are the best fit, are able to choose when they work, and ensure they focus on what's important to John and me in the ups and downs of his disease. When I really need a break, I can get one. CSIL is a lifesaver."

– Brenda, Caregiver

How are we helping?

Support for caregivers can come in many forms and the efficacy of the support can vary depending on the individual needs of the caregivers. Support required for some may be emotional, for others it is financial, and some may need assistance with navigating the system. What almost all caregivers have in common is a view that there is a benefit to finding and receiving respite from their caregiving duties.

It is not possible to reliably assess many of these interventions and their impact on the alleviation of caregiver distress with currently available data. However, data are available on the utilization of respite services through the Home and Community Care program, and these data can be linked to RAI-HC assessment data from the home support client and their caregiver.

The B.C. Home and Community Care program offers respite for caregivers through three programs:

1) **Adult day programs** (ADP), which allow clients to go to a centre staffed with health care professionals who work with clients to engage them in activities, provide a meal, and, in some cases, offer bathing. The caregiver is offered respite for the approximately seven hours the client is out of the home attending the program.
2) **Home support** provides professional care and support for tasks such as bathing, dressing, toileting and medication management. Some clients and their caregiver are able to access actual respite through shifts of time (typically two to four hours) that will allow caregivers to attend to their personal business outside of the home.
3) **Residential care respite** functions as a temporary stay in residential care. An eligible client is admitted for a set period of time, such as one to two weeks, providing the caregiver with an extended break in caregiving.

All three services charge a fee; ADP has a maximum cost of $10 per day, residential care respite has a fixed fee of $36.30 per day (adjusted annually to reflect inflation), and home support is charged at a daily rate based on income (a client in receipt of the federal Guaranteed Income Supplement (GIS) is exempt from this fee). In the case of undue financial burden on a client or their family, a reduction in fees may be obtained.

In assessing these respite programs and determining whether they are addressing changing needs, we looked at them within the context of what we would expect to see given the changing demographics and clinical characteristics of home support clients over the past two years. Over the past two years we know that the **complexity of home support clients has increased**, and the **level of caregiver distress** has **increased 7% to 31%, while** the **absolute number of distressed caregivers has increased by 14%** to a total of around 8,500 (from around 7,500). We also know that levels observed in our 2015 report were found to be inadequate. Given this context, we would expect to see increased access to respite resources in the two years since our last report was published.

In addition, the number of home support clients has increased by 4%; along with rising levels of care needs, this indicates a need to increase service levels to maintain the status quo. However, what we found was that access to respite services by those receiving home support has, in fact, decreased since 2015 – not only have we not made progress over the situation highlighted in the 2015 report, we have not even kept pace with population increase and rising care needs.

As the tables on the next page demonstrate, while the number of people receiving home support grew by 4% in the last two years[9]:

- The number of home support **clients accessing ADP decreased by 5%** and the number of days delivered to these clients decreased by 2%. The overall impact is a smaller number of individual clients are accessing more days per year, on average.
- The number of **home support** hours for clients 65 or older increased by 2%, but the **average hours per day per client decreased by 5%**, signalling less intensive service.
- The number of **residential care respite clients increased by 5%** and **admissions increased by 8%**. This suggests that only residential care respite expanded in response to the growing needs of home support clients and their caregivers, although **average length of stay decreased** in four of five health authorities, and we know from our 2015 report that only 11% of home support clients accessed residential care respite.

At a more granular level, further patterns emerge. While residential care respite appears to be growing sufficiently at a provincial level, this is concentrated in the Fraser Health Authority and Vancouver Coastal Health Authority; the other three health authorities saw a decrease in clients, admissions, or both. For home support clients, analysis later in this report shows that access is actually decreasing for the 85 or older age group. Not only are services intended to support caregivers largely failing to keep pace with the growth in home support, but the growth in the home support program itself is likely too low to meet the needs of B.C.'s oldest residents. Finally, the following breakdown shows that some service volume levels are still lower than they were four years ago.

Adult Day Program

Jim and Carole were enjoying retirement until Carole's stroke changed everything. Carole survived and, after rehabilitation, moved back home. Jim supported her 24/7, only reluctantly accepting home support services as his own health began to decline. Carole was on the waitlist for an Adult Day Program, but when openings came up, they declined – twice. Talking with a Caregiver Consult changed his mind.

"At first it was hard – very hard – to look my wife in the eye and tell her that she's going to the program. She cried, I hugged her, and I left her. I didn't know it at the time, but it was my best decision. It took us a while to get there, but both of us benefit. I still feel guilty, but I also could not carry on without the break ADP provides. Thank you for helping me to find the courage to try it."

– Jim, Caregiver

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[9] Between 2013/14 and 2015/16.

Adult Day Programs – Number of Clients (also utilizing home support)

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	1,000	944	944	948	929	↓ 2%
FHA	928	798	900	875	893	↓ 1%
VCHA	689	751	711	703	640	↓ 10%
VIHA	743	678	780	757	725	↓ 7%
NHA	207	211	206	174	162	↓ 21%
B.C.	3,563	3,372	3,535	3,450	3,345	↓ 5%

Adult Day Programs – Number of Days Utilized (also utilizing home support)

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	36,952	34,109	34,459	33,055	35,249	↑ 2%
FHA	32,503	31,784	34,624	35,524	35,301	↑ 2%
VCHA	31,038	33,347	30,367	29,333	27,821	↓ 8%
VIHA	27,540	24,716	26,568	29,635	28,423	↑ 7%
NHA	8,208	7,734	8,961	6,591	5,491	↓ 39%
B.C.	136,240	131,690	134,978	134,138	132,284	↓ 2%

Adult Day Programs – Average Days Accessed per Year (also utilizing home support)

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	37	36	37	35	38	↑ 4%
FHA	35	40	38	41	40	↑ 3%
VCHA	45	44	43	42	43	↑ 2%
VIHA	37	36	34	39	39	↑ 15%
NHA	40	37	44	38	34	↓ 22%
B.C.	38	39	38	39	40	↑ 4%

Residential Care Respite – Client Counts (Unique Clients)

	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	941	963	950	922	↓ 4%
FHA	519	544	570	672	↑ 24%
VCHA[10]	262	289	275	338	↑ 17%
VIHA	674	646	700	632	↓ 2%
NHA	248	246	234	251	↑ 2%
B.C.	2,644	2,688	2,729	2,815	↑ 5%

Source: Health authority direct request

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[10] Vancouver Coastal Health Authority is in the process of changing its reporting systems. As a result, 2015/16 data on residential care respite services is not directly comparable with data from 2014/15 and earlier.

Residential Care Respite – Admissions

	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	1,366	1,427	1,353	1,350	↓ 5%
FHA	818	864	899	1,134	↑ 31%
VCHA[10]	409	454	501	505	↑ 11%
VIHA	1,193	1,177	1,267	1,277	↑ 8%
NHA	340	378	350	368	↓ 3%
B.C.	4,126	4,300	4,370	4,634	↑ 8%

Source: Health authority direct request

Residential Care Respite – Average Length of Stay

	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
IHA	15.1	15.2	14.9	14.2	↓ 7%
FHA	9.2	9.4	8.9	8.0	↓ 15%
VCHA[10]	22.5	21.1	21	18.4	↓ 13%
VIHA	9.6	9.5	9	9	↓ 5%
NHA	18.1	16.7	14.6	26.9	↑ 61%

Source: Health authority direct request

In addition to ADP and residential care respite, home support itself is a key service to support caregivers. Stand-alone home support respite is defined as a block of two to four hours provided at a time convenient to the caregiver to allow them to attend to their own activities outside the home. The respite hours may or may not be attached to times when the client is receiving actual care, such as in the morning, depending on the needs of the caregiver.

As noted in our 2015 report, it is not possible to determine how much stand-alone respite home support was delivered to clients from the data sources available. We were also advised that consistent policies on access to, and allocation of hours for respite home support may differ between health authorities or even within health authorities. From this, we conclude that respite through the home support program is not seen as a priority for health authorities and we have not achieved the culture shift necessary to view respite as a key service to ensuring seniors are able to remain living in the community for as long as possible.

Notwithstanding the lack of data on stand-alone respite home support, we did analyze the hours of home support, recognizing that some respite is achieved when paid caregivers take on some of the care duties.

As with the other supports, we found that the amount of service offered on a per-client basis declined in the past two years, despite the increasing complexity of clients. The actual number of clients and the actual number of hours did increase but the number of hours

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per client decreased. This could be explained if we saw an attendant decrease in complexity of client needs, but the increase in complexity would indicate we should see an increase in the average number of hours per client.

We further analyzed clients and service levels by age groups. It is true that, not only is the population on average living longer, we are also living healthier for a longer period of time and possibly delaying the age at which we access services. This, however, is a delay and not an elimination of the need for services. As such, one might expect to see increases in the older age groups offset by decreases in the younger age group. Yet, as the data below illustrate, in the 85 or older age group, there has been both a decline in clients per 1,000 people and a decline in hours delivered to each client on a yearly basis. Not only are relatively fewer clients receiving home support, but those clients 85 or older who are receiving home support are receiving fewer hours per client compared to two years ago.

Finally, when we look at the use of home support respite services as a means of delaying or preventing admission to residential care, the data show that we are offering less support to clients and their caregivers despite increasingly complex care needs. This means that the care burden is likely shifting from the paid caregiver to the family caregiver and, as a result, the rate of caregiver distress is increasing, possibly resulting in seniors moving to residential care because their loved ones can no longer cope with the increased demands of care. This is counter to both the goal of supporting seniors to live as long as possible in the community and good fiscal stewardship, as facility care costs more than living at home with home support (based on funding four hours per day or 120 hours per month of home support compared to the cost of residential care – approximately $210 per day).

While the OSA will address the specific topic of home support in a separate report later in 2017, data related to respite services for caregivers in this report show that the home support program, within this context, is not performing to its full potential.

Seniors Population in B.C.

	2012	2013	2014	2015	2016	Change 2014 -> 2016
65+	718,821	752,128	784,876	817,616	850,424	↑ 8%
75+	323,017	332,321	342,585	353,148	365,510	↑ 7%
85+	95,038	98,899	103,172	107,377	111,846	↑ 8%

Source: BC Stats Population Estimates

Home Support – Clients aged 65 or older

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
Clients	32,335	33,157	34,893	36,231	37,059	↑ 6%
Hours	6,828,278	7,386,806	7,932,041	8,108,816	8,127,540	↑ 2%
Clients per 1,000 population	47	46	46	46	46	↓ 2%
Hours per client per year	211	223	227	224	219	↓ 4%
Hours per day per client	1.78	2.02	2.00	1.94	1.90	↓ 5%

Home Support – Clients aged 75 or older

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
Clients	27,203	27,652	29,008	30,191	30,838	↑ 6%
Hours	5,716,927	6,103,800	6,531,108	6,684,365	6,643,420	↑ 2%
Clients per 1,000 population	85	84	85	85	83	↓ 1%
Hours per client per year	210	221	225	221	215	↓ 4%
Hours per day per client	1.76	1.97	1.95	1.88	1.83	↓ 6%

Home Support – Clients aged 85 or older

	2011/12	2012/13	2013/14	2014/15	2015/16	Change 13/14 -> 15/16
Clients	15,955	16,236	17,108	18,100	18,640	↑ 9%
Hours	3,647,539	3,837,518	4,131,594	4,241,947	4,207,138	↑ 2%
Clients per 1,000 population	174	168	169	171	168	↓ 1%
Hours per client per year	229	236	242	234	226	↓ 7%
Hours per day per client	1.77	1.96	1.92	1.86	1.79	↓ 7%

Recommendations

1. Increase adult day program access

There needs to be a focused effort on increased promotion of ADP with a concomitant increase in the number of spaces.

As in our previous report, we recommend first looking at existing centres and creating two shifts of ADP per day – the first shift would centre around lunch, with arrival in mid-morning and departure mid-afternoon, while the second shift would centre around dinner, with arrival in mid-afternoon and departure in the early evening. This model would potentially allow a significant increase in capacity without incurring added infrastructure costs. There is evidence to support that an evening-based program is actually better for some clients and their caregivers.

Expanding services to include Saturday and Sunday should also be considered as another cost effective way to increase capacity without adding to infrastructure.

To ensure that ADP appeals to, and is suitable for, a wide range of clients, there is a need for different types of programs to reflect the different needs of clients. Younger clients with cognitive impairments from dementia but high levels of physical functioning need different programming and activities to engage them in contrast to older clients with dementia, who are more likely to also have attendant physical impairments. Lastly, not all home support clients in need of the respite offered by a day program have dementia, and there is a need for programs that recognize this.

2. Increase home support

Home support is not adequately meeting the needs of clients and their caregivers on two levels. First, home support services levels are not keeping pace with the growth in B.C.'s seniors population – the hours to provide actual care have been decreasing, while care needs have been increasing; this trend is not sustainable and needs to be reversed. Second, respite needs to be recognized as a legitimate care need.

Respite is offered to caregivers who cannot leave their loved one unattended. Given this, it is reasonable to conclude that respite needs to be offered in a block of time that will allow the caregiver to leave the home and attend to errands and appointments. While everyone's situation is different, there should be a well-articulated provincial policy for health authorities to follow in authorizing respite. The policy should indicate the minimum number of respite hours a caregiver is entitled to on a weekly or monthly basis, and should explicitly state that when and how those hours are provided is at the discretion of the caregiver.

Health authorities should code respite hours in their scheduling software and report at a provincial level to the Ministry of Health to enable tracking and assessment of respite home support hours.

3. Improve access to CSIL

There is compelling evidence of substantially lower rates of distress for caregivers of clients with equal or greater care needs when the client is registered under the CSIL program and can direct their own care. In addition, CSIL is more cost effective for the health care system. When health professionals are determining the number of hours of care per day and additional respite hours they will authorize for the client, clients and family members should be advised that they have two options: health authority-delivered care (either directly or through a contracted agency) or CSIL. The CSIL application process must be streamlined and consistently applied throughout the province.

4. Re-organize respite beds and increase the capacity

We encourage health authorities to look at models of respite care that cluster a group of beds – ten or more – in a single location. It can be a discrete unit within an existing care facility or a dedicated facility. The crucial point is that the unit function, in its entirety, as a respite unit. Admission and discharge procedures, programming and staffing will all be calibrated to recognize that people will be staying for short periods of time and have a permanent residence to return to. The current model of two or three beds in a facility being offered as respite (and potentially being filled by a permanent resident if there are space constraints) is not adequately fulfilling the role of respite. Confidence in the availability of the bed for respite is not absolute and the addition of respite clients can be disruptive to the other residents, potentially leaving the respite client feeling alone and isolated as they try to join an existing, permanent community. The critical mass that can be achieved through clustering respite beds – where everyone staying there is visiting for a short period of time – will create a better community of interest for the residents.

5. Empower caregivers

The importance of clear identification of the caregiving role cannot be underestimated. Numerous research studies from jurisdictions around the world highlight the fact that a person not recognizing they are a caregiver with very specific roles and responsibilities can mean missing out on critical supports and services.

Findings from the UK's *State of Caring Survey 2016* demonstrate that by not receiving support at an early stage, negative impacts of care intensified – from long-term physical health effects, to mental health, and social isolation. The survey found that 54% of caregivers took over one year to recognize their caregiving role and 24% took over five years to identify as a caregiver.

While there are many more caregivers than those we identified as supporting clients within the home support program, for those who access home support, the home support program provides a common interface. The home support program should act as a central access point for information on community supports and resources. We recommend that the province work with an organization, such as the Family Caregivers of BC, to develop a standardized format for health professionals to provide all home support clients and their caregivers with information on accessing the local caregiving supports and resources in their community. Consideration should be given to developing a consent policy that would allow a direct referral, by the health professional, to local resource groups.

Not only do caregivers need more support, they also need to feel confident in their ability to provide the care their loved one needs. Data clearly show that many family caregivers are providing the same types of care that formal care provides, yet there is no training available to support them; how to bathe someone, how to do a proper transfer, and how to monitor health status are all tasks that many family caregivers need to know. We recommend that the province work with provincial caregiver advocates to develop a standardized online training module to which health professionals could refer family members.

Conclusions

Data highlighted in this report indicate that there is a significant need to focus on system-wide strategies to support caregivers. The importance and impact of caregivers cannot be underestimated at a system level. Nationally, more than one in four Canadians are caregivers providing more than 80 percent of the care needed by their loved ones. As the population ages, both nationally and provincially, the time commitment and strain on sons, daughters, wives, husbands, neighbours, and friends of seniors with growing health care needs will inevitably become more acute if adequate supports are not carefully planned for – and accessed – to their maximum potential.

In terms of the B.C. perspective, the data available for home support clients – a subset of the overall caregiving network – highlights that, over the last two years, distress among caregivers is increasing, while supports available to them such as respite and adult day programs are staying flat or decreasing. This trend is particularly concerning as data also reveals that the health needs of the seniors being supported by caregivers are also getting increasingly complex, further adding to the demands on caregivers.

Recommendations included in this report, such as: increasing service levels of, and access to, respite and adult day programs; providing education and training to informal caregivers; and increasing additional supports and services such as psychosocial connections, must be a priority for both government and health care service providers. In addition, expanding access to the CSIL program will give clients and caregivers more choice and flexibility in how they choose to arrange their own home support services in a way that meets their unique needs.

The Seniors Advocate is confident that we all want what is best for our seniors and that caregivers need our support as well as our gratitude. This report has highlighted areas where we can make improvements that will make a real difference in the lives of many care givers. Implementing these recommendations will not fix all the problems or eradicate caregiver distress, but it will show that we can do better and that we are moving in the right direction given what lies ahead. We will continue to track caregiver distress, as well as the availability of services and supports year-over-year, and will continue to publicly report on progress in this important area.

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