

# Caregivers in Distress A Growing Problem



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**SENIORS** ADVOCATE

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# Caregivers

- ❖ It is estimated there are approximately 1 million unpaid caregivers in the province<sup>1</sup>
- ❖ Caregiver activities:
  - ❖ Can range from a ride to the grocery store or a medical appointment to assistance with everyday activities, such as bathing, toileting or medication management
- ❖ Replacing the care they provide with care from paid caregivers has an estimated cost of \$3.5 billion in B.C.

<sup>1</sup>Statistics Canada GSS Survey 2012. Proportional calculation based on number of seniors in B.C relative to Canada as a whole.



# This Report

- ◆ Focuses on caregiver distress for those providing informal care to clients receiving publicly-subsidized home support services in B.C.
- ◆ Why this focus?
  - ◆ The availability of robust, comparable assessment data for home support clients
  - ◆ These clients represent the most highly vulnerable seniors who without caregivers would likely need to move to a supportive living environment



# Caregivers in Distress: A Growing Problem

- ◆ This report updates and compares data and analysis from the OSA's 2015 report *Caregivers in Distress: More Respite Needed*
- ◆ Our 2015 report:
  - ◆ Found B.C. had one of the highest levels of caregiver distress in the country
  - ◆ Made recommendations on the need to improve supports for caregivers including increasing service levels for Adult Day Programs, respite beds and home support
- ◆ Two years later – how are we doing?



# How are we doing? Not very well

- ◆ Compared to 2 years ago:
  - ◆ Rate of caregiver distress **↑7%**
  - ◆ Hours per day of home support for 65+ **↓5%**, for 85+ **↓7%**
  - ◆ ADP clients **↓5%**
  - ◆ ADP days **↓2%**
  - ◆ Respite clients **↑5%** but average LOS **↓** in 4 of 5 Health Authorities

Burden is shifting from public system to family caregivers

# Analysis: Who are we caring for?

- There are 30,363 clients receiving long term home support

Characteristics	2015/16	Two Year Change
Age	82.3	↑2%
Activities of Daily Living (ADL 3+)	20%	↑7%
Moderate to severe cognitive impairment	21%	↑7%
*MAPLe 4+	52%	↑4%
Dementia	32%	↑4%
Aggressive behaviour	12%	↑7%
Difficulty with medication management	72%	↑4%

\*MAPLe – Method for Assigning Priority Levels



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# Who is providing care?

- ◆ 91% of primary caregivers were family members
  - ◆ 58% were adult children
  - ◆ 21% were a spouse
  - ◆ 12% were other family members
- ◆ On average, caregivers provide 20 hours per week of informal care
  - ◆ Co-residing caregiver – 32 hours per week
  - ◆ Not co-residing – 11 hours per week



# How are caregivers coping?

- ❖ In 2015/16, **31% of clients** had a primary caregiver in distress
- ❖ This is a **7% increase** over what we found in the 2015 report
- ❖ Over this period, the actual number of primary caregivers identifying as distressed **increased by over 1,000**
- ❖ This represents a **14% increase** in the actual number of caregivers in distress

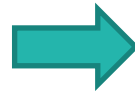




# What increases risk of distress?

## Client Factors

Mild cognitive impairment



almost doubles the risk

Moderate to severe  
impairment



triples the risk

Potential or actual  
problem with depression



over doubles the risk

Dementia



25% increased risk

The presence of any  
behavioural and  
psychological symptoms of  
dementia



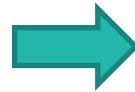
75% increased risk



# What increases risk of distress?

## Caregiver Factors

Being a spouse



80% increased risk\*

Being a co-residing caregiver who is not a spouse



40% increased risk\*

Higher levels of informal care hours



Mild increase in risk

\*relative to non-co-residing caregiver (any relation)



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# Effect of co-residing on distress

Rate of Distress	
<b>Co-residing Caregiver</b>	
Spouse	48%
Adult child	38%
<b>Non-residing Caregiver</b>	
Adult child	26%
Other relative	22%
Friend or neighbour	15%



# Potential tensions

- ❖ Overall, **20%** of home support clients feel they would be better off living somewhere else, compared to **29%** from their caregivers' perspectives
- ❖ Where clients are assessed as having a higher risk or probability of admission to residential care, **23%** of clients believe they would be better off living somewhere else compared to **39%** of caregivers
- ❖ Potential for increased caregiver distress 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



# More control – less distress

- ❖ **Choices in Supports for Independent Living (CSIL)** is a program that allows clients to receive money directly from their health authority and use that money to pay for the care they need
- ❖ 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



# How can we help?

- ◆ The number of home support **clients accessing ADP** **↓ by 5%** and the number of days delivered to these clients **↓ by 2%**
- ◆ The average hours of **home support per day per client** **↓ by 5%** for clients 65 or older, and **↓ 7%** for 85 or older, signalling less intensive service
- ◆ The number of **residential care respite clients** **↑ by 5%** and admissions **↑ by 8%**, but average length of stay **↓** in four of five health authorities



# Additional caregiver support

- ◆ Beyond increased service levels, how can service providers better support caregivers?
  - ◆ Develop strategies to identify caregivers earlier
  - ◆ Link caregivers with community supports
  - ◆ Provide training and education for caregivers so that they feel confidence in their caregiving skills



# Recommendations

1. Increase adult day program access
2. Increase home support hours and recognize respite hours as a need
3. Improve access to CSIL
4. Re-organize respite beds and increase the capacity
5. Empower caregivers





# Contact

[www.seniorsadvocatebc.ca](http://www.seniorsadvocatebc.ca)

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