THE FIRST ANNUAL BCCPA CARE TO DEBATE BC CARE PROVIDERS ASSOCIATION CONFERENCE

Facilitating Public-Private Partnerships to Reduce Caregiver Burden

Resolved that, a major city municipality create a management level position, entitled the Chief Policy Officer, to facilitate public private partnerships (PPP's) that would be focused on reducing caregiver burden with the creation of Carers' Policy within the workplace, or as a law at a city level.

Applicant: Daniel Wanis-Ruiz Sponsor: N/A

ISSUE

The uncompensated work hours for informal caregivers could be one of the greatest economic opportunities to improve lives and create wealth across Canada. Here are the 3 major reasons why more money in the pockets of informal caregivers helps everyone. First, financial stress is regarded as a major risk factor for caregiver burden. Caregiver burden has been documented to drain economic resources and impact the quality of life of families, particularly women who have been historically assigned caregiver roles (Mitchell & Hoffman, 1998; Adelman et al., 2014). Second, financial resources help caregivers pay for out of pocket costs, which can include medicine, travel, and formal caregiving services for their loved ones. In 2015, it was estimated 48% of caregivers in the US spent more than \$5000 (US) in out-of-pocket costs caring for their family and caring for someone with dementia can cost up to \$71,000 (US) (Press Room, 2014; Caring.com, 2015). Finally, unpaid caregiver hours from absenteeism, leave from work, turnover costs all contribute to the \$5.5 billion (CAD) lost annually for not supporting caregivers in Canada. In fact, research in the US has shown that supporting caregivers at their jobs for 5 care hours per week can save governments \$613 million - \$4.4 billion (US) (Feinburg, Reinhard, Houser, & Choula, 2011; AARP, 2013; Jacobs et al, 2013). Keeping caregivers in the workplace decreases risk of caregiver burden, indirectly supports older adults in an aging population, and can increase the amount of economic taxation in British Columbia and Canada.

BACKGROUND

During the late 18th century, nursing and caring emerged simultaneously in a large part due to the American Civil War and the Nightingale influence (Reverby, 1987). Both revolved around "women's work" and when the American Civil War broke out in 1861 the burden of care was placed on nurses and physicians (Basler, 1962). Prior to the 1950's, research on caregiver burden was scarce. However, as more research was published, caregiver burden was defined as "any cost to the family" and women inherited the role of caregiver formally and informally, as well as the adverse affects on quality of life and resources (Reverby, 1987). Today, caregivers, especially women, are still confronted with the same economic, social, emotional, and physical challenges and this issue is compounded by global aging

demographics and decreasing birthrates (Statistics Canada, 2015). Canada, along with many nations and cities are working to reduce caregiver burden, support those who need caregiving, and boost economic value.

During 2016, The City of San Francisco passed the Paid Sick Leave Ordinance Policy (PSLO) allowing employees to accrue sick days by providing 1 hour for every 30 hours worked, up to 40 hours per year for caregiving and self care (Chen, 2016). In Japan, The National Long Term Care Program supports caregivers and those they care for, offering subsidies for community supports (Forbes, 2015; Ministry of Health and Labour, 2017). In Canada, organizations such as the Alzheimer Society of Canada, and provincial and federal governments offer self care and respite services, Caregiver Tax Deductions, educational supports, and community supports (Canadian Caregivers Coalition [CCC], 2014; Alzheimer Society of Canada, 2017). Even with all this, there is not one person, organization, or system that isn't affected by not placing more money in the hands of caregivers. In the United States the American Association of Retired Persons (AARP) estimated there is an economic loss of \$470 billion in unpaid contributions of 40 million family caregivers (American Association of Retired Persons [AARP], 2013). To put this into perspective, that is approximately the equivalent to the revenues of 3 largest public companies in the world, and none of it was taxed (Forbes, 2016). If this is mirrored in Canada, this is the most important issue today because it affords our society the rare opportunity to make more capital by improving the lives of people. Starting tomorrow, we can start adapting models that have succeeded in other countries here to accommodate the aging demographic.

CONSIDERATIONS

In general, there have been 3 broad range approaches to helping informal caregivers financially. The first is employer level supports including flexible time schedules, 4-day work weeks, and short time notice paid leave (EFC, 2015, Forbes, 2015). The problem with this approach is that even when policies including the above are enforced by law, they are not always implemented or taken advantage of due to the political view that organizational costs will increase (Chen, 2016). The second, are tax credits and deductions. In Canada, line 315 has been written and implemented into tax forms to allow caregivers tax deductions on their annual income (Canada Revenue Agency, 2016). However, tax credits assume the family/informal caregiver have the out-of-pocket expenses to begin with and this can be problematic as costs associated with dementia, for example, care can reach \$71,000 (US) (Caring.com. 2015). Finally, subsidies are offered to support community services, respite, home care, end of life care, adult day services, rehabilitation services and others (Government of British Columbia, 2016). However, subsidized services are another point for political debate because the diversity and availability of services, such as respite, have decreased over the years in BC, according to a Seniors Advocate Report in 2014 (Office of the Seniors Advocate, 2014). If further financial support for informal caregivers is not built upon what is already in the market our nation will continue to lose \$5.5 billion (CAD) meaning less taxable income, less income and savings for the caregiver, and therefore, more demand on public healthcare services. (Lily, 2011; Chen, 2014). Additionally, unsupported caregiver burden reaching extremes similar to Japan during the 1990's and 2000's is detrimental to quality of life of seniors. During that time, national research recorded numerous accounts of elder abuse, decreases of informal caregivers in society, and therefore, increases in senior care costs for the government (Yamada, 1999; Sasaki et al., 2007). Therefore, the motion of this brief is to mandate the creation of a municipal level government position, that has the authority to create public-private partnerships (PPP's), policy, and networks with the one goal of implementation of carers' policy in the workplace. Within this brief, the position will be labelled Chief Policy Officer (CPO) and the proposed policy will be

similar to the San Francisco PSLO Policy, ensuring that workers can amalgamate sick day/care hours for caregiving regardless of being part time, full-time, or contractual (Chen, 2016). However, this will not begin as law, as testing the affect of such a policy is necessary in design creating a strong foundation for support is necessary (IDEO, 2015). It is hypothesized that this position will increase money in the pockets of informal caregivers, businesses, and governments alike while decreasing caregiver burden. Sustainability of such a program would be maintained because the policy would have to be motivationally accepted by the employer, geared towards long term success, facilitated by the government, and evaluated using user centered design principles (von Hippel, Thornke, & Sonnack, 1999; IDEO, 2015). Spread can be achieved using stakeholder networks currently in place within municipalities and newly created networks that have strong economic influences in Vancouver through word of mouth communications to all levels of society (De Bruyan & Lilien, 2008). Once larger companies accept or implement policies such as this, denying their financial value will be less debatable and movement towards creation of carers' policy laws will have more support in the future (Kotter, 1998; EFC, 2013; Chen, 2016).

NEXT STEPS

First, lobbying for the creation of the CPO position within 1 city municipality in British Columbia for 2 years would be necessary. Assuming, this is possible, the next steps would include preparation (6 months), ideation (6 months), and implementation (1 year) (IDEO, 2015). Preparation is the most important phase in creation of this initiative and will be focused on here. The first 6 months of preparation include building networks with 4 major stakeholder groups to understand the challenge of creating a carers' policy. The first stakeholder group is a researcher network that should include Dr. Jennifer Baumbasch, Dr. Paddy Rodney, and Dr. Darren Dahl from the Faculty of Nursing and Sauder School of Business at UBC as they can help understand the challenges with integration of caregiver policy within organizations (UBC, 2017). Including Dr. Andrew Wister from the SFU can provide insight into family and social support in elder populations and the social affect of a carers' policy (SFU, 2017). The second stakeholder group would be public sector representation. Many organizations such as The Alzheimer Society, Family Caregivers of British Columbia, Agewell, City Age, CCHL, the health authorities in BC, the provincial government, and any other vast network that houses employed professionals, all have an investment in supporting caregivers currently and therefore should be considered as partners. Their knowledge is vast and support from all levels of the province is necessary for success of any long term program (Kotter, 1998). Third, businesses must be directly involved because they are the ones that will be taking the risk, but reaping the rewards in the PPP. Therefore, making sure there is clear communication with them from the very beginning is required for project implementation. Examples include Price Waterhouse Cooper, Deloitte, and small businesses in Vancouver. Finally, informal caregivers should be involved at every step of the project implementation because they are the most involved stakeholder alongside the employer. Their input during beta testing and evaluation of any carers' policy is invaluable to the adaptation of the initiative to each environment. Fair process is the main guideline of this approach (Chan Kim & Mauborgne, 1997).

REFERENCES

Adelman, R., Tmanova, L., Delgado, D., Dion, S., & Lachs, M. (2014). Caregiver burden: A clinical review. JAMA, 311(10), 1052–1060. JOUR. Retrieved from http://dx.doi.org/10.1001/jama.2014.304

Alzheimer Society of Canada. (2017). Other Resources for Caregivers. Retrieved from http://www.alzheimer.ca/en/We-can-

help/Resources/Resources-for-the-caregiver

- Briefing, E. F. C. (2015). January 2015 THE BUSINESS CASE FOR SUPPORTING WORKING CARERS The demographic drivers The business case for employers, (January), 1–6.
- Canada Revenue Agency. (2016). Line 315: Caregiver amount. Retrieved from <u>http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/315/menu-eng.html</u>

Canadian Caregiver Coalition. (2014). A Canadian Caregiver Strategy: Are We Making Progress?

Caring.com. (2015). Senior Care in 2015. Retrieved from https://www.caring.com/research/senior-care-in-2015

- Chappell, N. L., & Funk, L. M. (2011). Social Support, Caregiving, and Aging. *Canadian Journal on Aging*, *30*(3), 355–370. <u>http://doi.org/http://dx.doi.org/10.1017/S0714980811000316</u>
- Chan Kim, W., & Mauborgne, R. (1997). Fair Process: Managing in the Knowledge Economy. *Harvard Business Review*, 75(4), 65–75. http://doi.org/Article
- Chen, M. L. (2016). The growing costs and burden of family caregiving of older adults: A review of paid sick leave and family leave policies. *Gerontologist*, *56*(3), 391–396. <u>http://doi.org/10.1093/geront/gnu093</u>
- De Bruyn, A., & Lilien, G. L. (2008). A multi-stage model of word-of-mouth influence through viral marketing. *International Journal of Research in Marketing*, 25(3), 151–163. <u>http://doi.org/10.1016/j.ijresmar.2008.03.004</u>
- Employers for Carers. (2015). Caregiving Costly to Family Caregivers. Retrieved from <u>http://www.aarp.org/home-family/caregiving/info-2016/caregiving-costly-to-family-caregivers-jj.html</u>
- Family Caregivers of British Columbia. (2017). Provincial Resources for Family Caregivers. Retrieved from <u>http://www.familycaregiversbc.ca/resources/provincial-resources/</u>
- Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving. AARP Public Policy Institute, 28. Retrieved from <u>http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf</u>
- Forbes. (2015). What Japan Can Teach us About Long Term Care. Retrieved from
 https://www.forbes.com/sites/nextavenue/2015/08/24/what-japan-can-teach-us-about-long-term-care/#4f84a8d8705d
- Forbes. (2016). The Worlds Biggest Public Companies. Retrieved from <u>http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf</u>
- Government of British Columbia. (2016). Who Pays for Care. Retrieved from http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/who-pays-for-care
- Hoffmann, R. L., & Mitchell, A. M. (2005). Caregiver burden: historical development. *Nursing Forum*, 33(4), 5–11. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10205484
- IDEO. (2015). The Field Guide to Human Centered Design. Retrieved from http://www.designkit.org/resources/1
- Jacobs, J. C., Lilly, M. B., Ng, C., & Coyte, P. C. (2013). The fiscal impact of informal caregiving to home care recipients in Canada: How the intensity of care influences costs and benefits to government. *Social Science and Medicine*, *81*, 102–109. <u>http://doi.org/10.1016/j.socscimed.2012.12.015</u>
- Lai, D. W. L. (2012). Effect of Financial Costs on Caregiving Burden of Family Caregivers of Older Adults. SAGE Open, 2(4), 2158244012470467-. <u>http://doi.org/10.1177/2158244012470467</u>

- Lilly, M. B. (2011). The Hard Work of Balancing Employment and Caregiving: What Can Canadian Employers Do to Help? Healthcare Policy, 7(2), 23–31.
- Ministry of Health and Labour. (2017). Japan 2035: Leading the World Through Health. Retrieved from http://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/shakaihoshou/hokeniryou2035/future/en/
- Office of the Seniors Advocate British Columbia. (2015). Caregivers in Distress More Respite Needed, (September), 1–24. Retrieved from <u>https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2015/09/Caregivers-in-Distress-Report.pdf</u>
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). World Alzheimer Report 2016 Improving healthcare for people living with dementia. Coverage, Quality and costs now and in the future, 1–140. Retrieved from <u>https://www.alz.co.uk/research/world-report-2016</u>
- Press Room. (2014). Study: Baby Boomers Will Drive Explosion in Alzheimer's-Related Costs in Coming Decades. Retrieved from <u>https://pressroom.usc.edu/study-baby-boomers-will-drive-explosion-in-alzheimers-related-costs-in-coming-decades/</u>
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the Invaluable: 2015 Update. AARP Public Policy Institute, (July), 1–25. Retrieved from <u>http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-</u>2015-update-new.pdf
- Reverby, S. (1987). Ordered to care: The dilemma of American nursing, 1850-1945.
- Simon Fraser University. (2017). Faculty. Retrieved from https://www.sfu.ca/gerontology/people1/faculty/dr--andrew wister.html
- Schiamberg, L. B., & Ma, D. G. (2008). An Ecological Framework for Contextual Risk Factors in Elder Abuse by Adult Children An Ecological Framework for Contextual Risk Factors in Elder Abuse by Adult Children, 6566(October 2014), 37–41. <u>http://doi.org/10.1300/J084v11n01</u>
- Statistics Canada. (2015). Canada's population estimates: Age and sex, July 1, 2015. Retrieved from http://www.statcan.gc.ca/daily-quotidien/150929/dq150929b-eng.htm

University of British Columbia. (2017). Faculty. Retrieved from https://nursing.ubc.ca/our-people/faculty

von Hippel, E., Thomke, S., & Sonnack, M. (1999). Creating breakthroughs at 3M. *Harvard Business Review*, 77(5). http://doi.org/10.1038/nbt1001-921

OTHER INFORMATION:

Who can we speak to for more information?

My name is Daniel Wanis-Ruiz and my major inspiration was from Dr. Janet Fast from the University of Alberta. Knowledge of caregiver policy in the workplace came from her research. Employers for Carers, in the United Kingdom have strong backing from British Gas representative Ian Peters as he spearheaded the carers policy implementation within British Gas.

Do you have supportive visual materials (existing video footage, still photography) that are relevant to this issue?

I have graphs and statistics that can be utilized during the debate.

Would you be available to speak to the media?

Yes, I would be able to speak to the media.

This brief was prepared in collaboration with: Daniel Wanis-Ruiz