

## **Project Background**

Worldwide the population is aging with nearly 900 million people over the age of 60. Life expectancy has steadily risen in Canada with the average number of years moving beyond 80 in 2015. As the population of older adults swells so too does the prevalence of age-related diseases like Alzheimer's disease or other related dementias. Advanced age and cognitive impairment reduce decision-making capacity. Family members may intervene and act as a guardian if an older adult is deemed incapable of managing decisions for their health or finances. However not all older adults have a family member or friend available to act as guardian.

Public guardians are appointed when a family member or friend is either unavailable or unwilling to take on the role and responsibility of legal decision-maker. Public guardianship is the legal mechanism for appointing responsibility for personal (e.g., health care decisions, living situation) or financial decisions to a surrogate decision maker.

Older adults placed under public guardianship lack both decision-making capacity and someone familiar with their care preferences to act as their representative. The combination of cognitive impairment and insufficient social support means that older adults under public guardianship typically reside in long-term care (LTC) facilities. Once living in LTC, public guardians are responsible for decision-making on behalf of the resident, but do not provide 'extras' not covered by the facility, such as special foods, clothing, uninsured health items (e.g., foot care, eye care) and toiletries. Individuals for whom no family or friend support is available are perhaps the most vulnerable older adult population, yet the least is known about their quality of life.

The **purpose** of my dissertation research was to determine the prevalence, characteristics, and unmet care needs of residents under public guardianship in Alberta LTC homes. My specific **objectives** were (1) to examine the conceptual framework of social exclusion in a LTC context to assess potentially unmet care needs of residents with public guardians, based on interviews with key stakeholders in LTC and in the Office of the Public Guardian and (2) assess the prevalence of public guardianship reporting by distributing an online survey to all 172 Alberta LTC homes.

### **Progress on Objectives**

**Objective 1:** I completed 42 interviews with care providers from seven LTC facilities from across Alberta (Edmonton, Red Deer, Calgary, Medicine Hat), and three public guardians from the Edmonton (n=2) and Calgary (n=1) Offices of the Public Guardian. I completed 3 validation focus groups to review the qualitative findings. We submitted an invited paper to the *Journals of Gerontology: Series B (Social Sciences)* Special Issue: Aging Alone. The citation is below.

Chamberlain, S.A., Duggelby, W., Teaster, P.B., Estabrooks, C.A. Characteristics and unmet care needs of unbefriended residents in long term care. *Journal of Gerontology: Series B*

**Objective 2:** I administered an online survey to all 172 LTC facilities in Alberta. The aim of the survey was to determine the prevalence of unbefriended residents in all Alberta long term care facilities. I received 123 responses (72% response rate). I have drafted the prevalence survey paper to be submitted to *Age and Ageing* (IF: 4.282). This paper will be submitted by April 30, 2018.