



**University
of Victoria**

Graduate Studies

PROGRAMME

The Final Oral Examination
for the Degree of

DOCTOR OF PHILOSOPHY
Department of Psychology

Megan Caines

2009	University of Victoria	MSc (Psychology)
2006	Acadia University	BA

“The “Hows” and “Whys” of Parental Future Planning for Adults with Intellectual Disabilities: An Interpretive Description Inquiry”

Wednesday, August 13, 2014
3:00 P.M.
University Centre, Room A207a

Supervisory Committee:

Dr. Holly Tuokko, Department of Psychology, UVic (Supervisor)
Dr. Colette Smart, Department of Psychology, UVic (Member)
Dr. Michael Hayes, Department of Public Health & Social Policy,
UVic (Outside Member)

External Examiner:

Dr. Nancy Jokinen, Department of Social Work, UNB

Chair of Oral Examination:

Dr, Vivienne Temple, Department of Exercise Science, Physical &
Health Education, UVic

Abstract

This study focuses on parental future planning for adults with intellectual disabilities. In recent years, the need for parents to engage in future planning for their offspring with intellectual disabilities has been increasingly emphasized. Within the literature, a number of approaches to future planning have been identified, including both formalized approaches (i.e., creating clear, explicit, and largely unchanging plans for the future of the individual with an intellectual disability) and more informal approaches (i.e., designating a Person or a group of people to oversee the well-being of the individual with an intellectual disability without necessarily providing specific guidelines relating to the individual's future care). Despite growing understanding that parents may approach developing future plans in different ways, to date, research on future planning has largely been focused on exploring formalized, concrete approaches to future planning. Using an Interpretive Description methodology, in which semi-structured interviews were conducted with 28 parents of adults with intellectual disabilities, this study sought to gain a greater understanding of parental future planning in real life practice in the province of British Columbia. Results revealed that while the parents in this study often utilized several future planning approaches -- both formal and informal -- when engaged in planning, they could be classified into two broad categories: Concrete Planners and Informal Planners. In addition, the results of this study also highlight key factors that may distinguish between parents who plan more formally and parents who plan more informally. Overall, these results highlight important avenues for future research and policy and practice; which, ultimately, may lead to important changes regarding how best to support aging parents of adult children with intellectual disabilities as they face the challenging task of planning for the post-parental care phase of their adult child's life.

Awards, Scholarships, Fellowships

- 2012 Research Fellowship, *University of Victoria*
- 2011 Council of Canadian Departments of Psychology
Teaching Assistant Award
- 2009-10 Alzheimer Society of Canada Doctoral Award
- 2009-10 President's Research Scholarship, *University of
Victoria*
- 2008 Exceptional Merit Award for Academic Achievement,
University of Victoria
- 2008 First Prize in British Columbia Psychogeriatric
Association's Student Poster Competition
- 2006-07 Social Sciences and Humanities Research
Council Master's Level Canada Graduate
Scholarship
- 2006 President's Research Scholarship, *University of
Victoria*
- 2006 University Medal in Psychology, *Acadia University*
- 2005 Honors Summer Research Award, *Acadia University*
- 2005 Dean of Arts Academic Excellence Award, *Acadia
University*
- 2005 Deans' List Scholarship, *Acadia University*
- 2004-05 Minnie Brown Cutten Memorial Scholarship,
Acadia University

Presentations

Caines, M.; Berlando, V.; Kissinger, B.; Hopkins, J. "Aging caregivers of adults with intellectual disabilities." Applied Research Colloquium, Victoria, B.C., Canada. 2012. (paper)

Caines, M.; Tuokko, H.; MacCourt, P.; Moselle, K. "A psychogeriatric tertiary care facility: The Sandringham experience." Canadian Coalition for Seniors Mental Health conference, Toronto, ON, Canada. 2008. (paper)

Caines, M.; Tuokko, H.; MacCourt, P.; Moselle, K. “*Tertiary psychogeriatric care: A collaborative experience.*” A Showcase of Research on Aging, Victoria, B.C., Canada. 2007. (paper)

Caines, M.; Tuokko, H.; MacCourt, P.; Moselle, K. “*A psychogeriatric tertiary care facility: The Sandringham experience.*” British Columbia Psychogeriatrics Association. Vancouver, B.C., Canada, 2007. (poster)

Caines, M. “*Health versus unhealthy approaches to relationships: Exploring lay conceptions.*” Atlantic Provinces Council on the Sciences (APICS), Cape Breton, NS, Canada. 2006. (paper)

Publications

Caines, M.; Tuokko, H.; Milliken, J. “The experiences of caregivers of older adults with dementia and non-dementia related mental illness: Similarities and differences.” *The Qualitative Report*. **(submitted)**.

Tuokko, H.; MacCourt, P. with assistance from Caines, M. “*Changes in Sandringham Care Centre residents over time: Tertiary psychogeriatric care (Final Report).*” *University of Victoria, Centre on Aging*. **2007**.