

THE CENTRE FOR RESEARCH ON PERSONHOOD IN DEMENTIA (CRPiD)

The Centre for Research on Personhood in Dementia (CRPiD) is an interdisciplinary team of practice-based and applied researchers who are committed to improving understanding and support for people living with dementia, their families and communities. We do this by:

- Conducting original research to create new knowledge
- Creating a strong research community including recruiting students and post-doctoral researchers, and welcoming visiting scholars.
- Assisting community partners to access and use relevant research

Interested in Volunteering?

[Fill out the online form and email \[alison.phinney@ubc.ca\]\(mailto:alison.phinney@ubc.ca\) \(cc \[paulina.malcolm@ubc.ca\]\(mailto:paulina.malcolm@ubc.ca\)\)](#)

ABOUT US

The Center for Research on Personhood in Dementia (CRPiD) is a BC-based virtual research centre located at UBC (Vancouver campus). Led by co-directors Deborah O'Connor (Social Work) and Alison Phinney (Nursing), the CRPD serves as a hub for research generation, training, and knowledge application around issues of personhood and citizenship in dementia. The CRPD includes researchers located at UBC and other universities in British Columbia.

What we do

We conduct theoretical and applied research aimed at understanding and supporting personhood and citizenship in dementia.

OUR WORK is situated in three intersecting domains: lived experiences, interactional environments, and socio-cultural contexts. The diagram beside represents this guiding framework.

History

The Centre for Research on Personhood in Dementia was founded in 2004 as an interdisciplinary research unit with funding from the Michael Smith Foundation for Health Research. The founding director was Deborah O'Connor (Social Work) and founding members were: Lynn Beattie (Geriatric Medicine); Habib Chaudhury (Gerontology, Simon Fraser University); Martha Donnelly (Family Medicine and Geriatric Psychiatry); Elisabeth Drance (Geriatric Psychiatry); Peter Graf (Psychology); Anne-Martin Matthews (Family Studies); JoAnn Perry (Nursing); Alison Phinney (Nursing); Barbara Purves

(Audiology and Speech Sciences); Jeff Small (Audiology and Speech Sciences); Andre Smith (Sociology).

The CRPiD Exchange: students and early career scholars community of practice

The CRPiD provides an interdisciplinary home for students, post-doctoral researchers, and visiting scholars who are conducting research on topics related to personhood and citizenship in dementia. We are a vibrant scholarly community with connections across BC, Canada, and internationally. We also work with an active network of community partners to help translate and mobilize new knowledge into real life settings.

Peer Mentoring: Building A SUPPORTIVE COMMUNITY of Masters, Doctoral and Post-Doctoral scholars.

Personal Development: A SAFE SPACE TO WORK through the bumps of graduate & post graduate studies.

Professional Development: Engaging in activities related to CAREER DEVELOPMENT.

Building Scholarship: CULTIVATING ACADEMIC FINESSE, developing rigour, testing & refining ideas.

(Integrated) Knowledge Translation: Presenting our work along the research process; articulating the IMPACT OF OUR RESEARCH.

MEMBERS

INVESTIGATORS

Deborah O'Connor, PhD, RSW (Co-Director)
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Habib Chaudhry, PhD

Chair and Professor in the Department of Gerontology, SFU Simon Fraser University

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Joan Braun

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Jim Mann, LL.D.

Researcher, Author, Volunteer, living with dementia

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Assistant Professor, School of Nursing, University of Victoria

CPRiD Education and Knowledge Translation Coordinator

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Shelley Canning, RN, PhD

Assistant Professor, Nursing Program, University of the Fraser Valley

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RESEARCH STAFF

Eric Macnaughton, Project Manager

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Samantha Pineda Sierra, Visual Communication Designer

Paulina Malcolm, Community Research Coordinator

TRAINEES

Current

Sheila Novek, PhD

CIHR Postdoctoral Fellow

University of British Columbia

CRPiD Student Connections Lead

Natasha Marriette, PhD

Doctoral Research Coordinator

University of British Columbia

Social Work

Completed

Mariko Sakamoto (PhD, Nursing)

Postdoctoral Fellow

Alternate Level of Care: Experiences of People with Dementia and Their Families

Publications

Shelley Canning (PhD, Nursing)

Social and Emotional Engagement of Older Adults Living with Dementia in Long Term

Residential Care

Publications

Lillian Hung (PhD, Nursing)

Nursing Care of Older People with Dementia in the Acute Care Setting

Publications

Gloria Puurveen (PhD, Interdisciplinary Studies)

Exploring the Experiences of People with Advanced Dementia Nearing the End of Life
Publications

Sienna Caspar (PhD, Interdisciplinary Studies, 2014)

The influence of information exchange processes on the provision of person-centred care in residential care facilities

Publications

Jennifer McDuff (MSN, Nursing, 2013)

Walking for Meaning in Dementia

Publications

Elizabeth Kelson (PhD, Interdisciplinary Studies, 2013)

Challenges of person-centred dementia care: a critical ethnography of culture change in long-term care

Publications

Sing Mei Chan (PhD, Social Work, 2012)

Exploring dementia care in Chinese immigrant families in Greater Vancouver, British Columbia, Canada

Publications

Louise Stern (PhD, Social Work, 2013)

The cultural whisper in our ear: intercultural dementia care in a Jewish long-term care facility

LIVED EXPERIENCE RESEARCH ADVISORS (LERA)

Myrna Norman

My name is Myrna Norman. Coming from Maple Ridge BC, a suburb of Vancouver, my life has taken a significant turn after being diagnosed with Frontal Temporal Dementia in 2009. Currently my diagnosis is MCD after being diagnosed with Lewy body and my drivers license removed by the doc, and Alzheimers, confusion reigned.

Could I be the only one with all of the difficulties in diagnosing? Could my passion for advocacy have spurred the neutrons in my brain to make better connections, who knows. Maybe, part of my advocacy misdoing a peer group for those with memory issues in my home town. Fun events like 'Christmas in July, October Fest celebrations, Christmas light bus trips and experiences with art, quizzes etc are part of our get togethers.

Some of the groups that offer highlights to my life are Early Persons Living with Dementia group, it's stimulating and energetic and enriching. The Dementia Sisterhood, the Action Committee, CCNA, Alzheimers Advisory, Dementia Advocacy Canada, Community Response Network, Dementia Friendly Task Force, Elder Law, Advance Care Planning and even more. Much to do and much to learn and to share, isn't that what life is all about? Won't you join me?

My involvement with Flipping Stigma unlocked and improved the neuron connections in my brain. Use it or lose it is so true. I am attempting to become a researcher and my first research project will be about 'sundowning'.

Granville Johnson

Granville Johnson, B.Ed. (UVic), Assoc Diploma, Writing in New Media (CNC), living with a Vascular Dementia diagnosis since 2016 and Converted Disorder since 2010. Granville is a Black dual citizen of Canada and America, and a two tour Viet Nam War veteran (combat medic), the beginning of a life direction dedicated to service.

A life-long artistic career was enhanced by attaining his Bachelor of Education at University of Victoria, British Columbia, Canada in 1986, leading to seven years teaching in the Northern British Columbia Public School system, from Primary, Intermediate, Secondary, through Adult Basic Education. He danced professionally for ten years after multi-disciplinary dance training in Modern, Contemporary, Jazz, Afro-Jazz techniques and Choreography, for four years. His artistic evolution involved into musicianship as a percussionist specializing in the Djembe, an African hand drum. To promote his performance events, he developed his interest with multimedia digital collage to create and produce media materials.

His inherent literary interest and a need to document his life's journey as a survivor of long term sexual and physical abuse, led him to enroll in the Writing in New Media Program at the College of New Caledonia (CNC), to graduate with an Associate Diploma (2yr.). After which he went on to further develop his skill set writing fiction: poetry, short story writing, and as a novelist.

Backstory: The Many Live of Granville Johnson, his first volume of a four-volume series, is soon to be released in Canada. Information about the novel and its author can be found at granvillejohnson.ca.

"I feel that my varied creative experience has greatly infused the self-awareness of my inner topography, that is being affected by the Vascular Dementia and the Converted Disorder, in real time.

While my extensive teaching and performance experience, has enhanced my ability to communicate effectively to others how the realities of living with dementia are experienced. Thus, I can facilitate awareness and the understanding of the changes within someone living with dementia, particularly in early onset and/or pre-diagnosis, as well as work to counter-act stigma within society.”

Granville, with his wife, Birgit Luesgen, discovered their journey toward self-advocacy and dementia community by participating in a month-long support group for people living with dementia and their care-person(s). The group was facilitated and moderated by the Alzheimer’s Society of British Columbia, in Prince George, Northern BC. The group met on four consecutive Wednesdays. From that modest beginning, Laurie Decroos, Alzheimer Society of BC – Northern Resource Centre, suggested that Granville join the Action Group, Flipping Stigma Project. It was with that group that Granville began his transition toward advocacy.

The creation of the resource, flippingstigma.com, catapulted the project’s People Living with Dementia (PLWD) membership into high demand, within the expanding participatory partners in research trend. As with many of the Action Group. Members, Granville began receiving many invitations to work with committees on other research projects. Some of the national and international project groups have included: The National Dementia Guidelines (NDG) Black Community Working Group, The Alzheimer’s Society of Canada, The I’m Still Me Project: Brella Society, Reimagining Dementia: A Creative Coalition for Justice, The-End-of-Life Project, Univ. of Waterloo, Ontario, University of Ottawa – Air Travel dementia - friendly project, Centre for Research on Personhood in Dementia (CRPiD).

Granville has co-written, w/ Karen Wong and Deborah O’Connor: “Living with Dementia: Exploring the Intersections of Race, culture and dementia stigma.” Granville, continuing to answer his calling of service, has been an outspoken Dementia advocate for six years, building resilience within the dementia journey. Facilitating Ethno-Racial Inclusivity in Dementia Research.

Lynn Jackson

Lynn Jackson was born in Richmond, British Columbia and is a proud member of the Saulteaux or Plains Ojibwe, sometimes referred to as the Anishanaabe. She began her career as a Registered Nurse at the Royal Jubilee Hospital in Victoria, BC where she completed her education. She then worked at Toronto General Hospital for several years before moving to Mexico City (and later Puerto Rico) in the early 90’s to pursue a job on the sales and promotional side of medicine. Lynn learned Spanish, joined a social running group, and made many lifelong friends there, several of whom she still connects with regularly. It was while living in Puerto Rico that she noticed something

had changed for her and she pursued medical treatment resulting in a diagnosis of frontotemporal dementia.

Since then, Lynn has participated in numerous Alzheimer's Disease International working groups helping its member countries become more inclusive of people with dementia. She is one of the founders of Dementia Advocacy and Support Network International DASN (2001), the world's very first internet-based organization by and for people diagnosed with early-stage dementia. While DASN's website is no longer live, many of its members are still very involved in advocacy roles around the world, continuing to build on the momentum of what they started. And Lynn is no exception! She works with UBC's IDEA Lab on projects like their Telepresence Robot Study and Calm Robot Study, a study called "Implementing Dementia-Friendly Care for Cancer Patients Living with Dementia," and another called "Learning Health Systems for Dementia Care Transition." Lynn is a vital member of the Flipping Stigma Action Group, also through the University of British Columbia, and an End-of-Life Project through the University of Waterloo. She's collaborating on "Innovation for Indigenous-led Dementia Care to Enhance Safety" through the University of Calgary, and she co-wrote an academic journal article with Dr. Lillian Hung for Perspectives called, "The Story of Elder Alex, A Reflection on Gerontological Nursing Competency Standards." She also served as a key research consultant for widely celebrated author Lisa Genova in the writing of the book "Still Alice" (later made into a critically acclaimed film starring Julianne Moore, Kristen Stewart and Alec Baldwin.)

Long-time Alzheimer's Society of BC staffer Barbara Lindsay described Lynn as "a dear friend, an effective advocate, and a wise volunteer."

Lynn's current interests include advocating for people with dementia and increasing awareness of Alzheimer's disease and related dementias. She has spoken locally, nationally, and internationally to promote better diagnosis, access to treatment and inclusiveness. Lynn has taken a particular interest in breaking the stigma surrounding a dementia diagnosis, and can be found speaking on panels, giving speeches and presentations, partaking in online discussions about outreach, and attending zoom meeting after zoom meeting for research and planning related to improving the quality of life for people living with dementia. She is a world traveler, a fierce and fearless advocate, and a vibrant and brilliant friend to those of us lucky enough to know her.

Sherri Adams

Sherri is a dancer at heart and is a big part of her community wherever she happens to be. She spends much of her days with friends in her community and is always looking for more opportunities to connect with others and learn about what is happening around her.

Having danced at the Junos, Sherri lives her life with an intrinsic rhythm and can often be found singing and dancing wherever she goes.

Sherri enjoyed being a part of the Flipping Stigma Action Group and continues to feel that being an advocate has been a positive experience and a great opportunity to both learn from others and share her own knowledge.

Donna Wager

PARTNERS AND COLLABORATORS

Myrna Norman, Granville Johnson, Lynn Jackson, Sherri Adams, Donna Wager

Research Collaborators

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Visiting Scholars

Emma Ferguson-Coleman, PhD

Social Research with Deaf People group and also to the Dementia and Ageing Research Team, University of Manchester.

2018

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Hildur Kalman, PhD, RPT

Professor of Social Work and Associate Professor of Philosophy of Science

Department of Social Work, Umeå University, Umeå, Sweden

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Niamh Hennelly, PhD student

National Centre for Social Research on Dementia, National University of Ireland Galway

2017

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Anne-Charlotte Nedlund, PhD

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2014

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Elsie Yan, PhD

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Clive Baldwin, PhD

Senior Lecturer, School of Dementia Studies, University of Bradford

2006

Murna Downs, PhD

Professor, School of Dementia Studies, University of Bradford

2006

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RESEARCH

Current

- Dementia + Decision Making Project

The CCEL Dementia + Decision-Making Project is an initiative to support the rights of people living with dementia in making decisions about their care and well-being. We developed a package of resources following extensive consultations with people living with dementia, their family members and friends, caregivers, care partners, and health care professionals to share practical and legal information about these issues. These resources include videos, practical guides, information pamphlets and decision-making flow charts.

This initiative is intended to support people living with dementia, as well as family or friend caregivers and care partners, and health care providers. The resources were developed based on the information gathered from all these perspectives to ensure that these materials can best serve these audiences.

The full package of resources can be found on the CCEL Dementia + Decision-Making Project webpage.

Assessing decision-making (in) capacity in the context of abuse and neglect

This socio-legal study is being co-lead by Deborah O'Connor and Joan Braun and is funded by Social Sciences and Humanities Council (SSHRC).

Research Team includes: Deborah O'Connor, Joan Braun (Law, Lakehead University), Margaret Hall (Law, SFU), Rachelle Hole (Social Work, UBC-O), Krista James (Law and policy development, Vancouver Coastal Health (VCH), Alison Leaney (BC Public Guardian & Trustee (PGT), Kelly Pursar. (Law, Queensland University), Natasha Marriette – Doctoral Research co-ordinator, Social Work, UBC

- Assessing decision-making capabilities in situations of abuse and neglect is recognized as an extremely complex and morally challenging area of professional practice. Internationally, the complexity of issues surrounding mental capacity (MC) are being grappled with at both the legislative and practice level. Article 12 of the UN Convention for the Rights of Persons with a Disability (CRPD) has been particularly influential in foregrounding the importance for a more nuanced, sophisticated understanding of MC that recognizes context, capabilities, and rights. This necessitates new approaches for understanding and assessing decision-making capability (DCM) – the process whereby MC is evaluated in practice - given that existing practices focuses almost exclusively on cognition.

The urgency to develop better understanding and practices related to decision-making capacity has particular significance for people living with dementia who routinely have their rights challenged because dementia-stigma and discrimination perpetuate misconceptions that those living with dementia are incapable and unable to participate in decision-making.

Drawing on a citizenship-in-practice lens, this study seeks to understand current practices in assessing decision making abilities for adults experiencing abuse and neglect in order to find better ways to conduct these assessments that ensure they are more humane, person-centred and consistent with the UN Convention of Rights of People with Disabilities (CRPD).

If you have any questions or are interested in learning more, please contact <Deborah.oconnor@ubc.ca> or <nmarriet@student.ubc.ca> 604-551-0459

- Flipping Stigma

Reducing Stigma and Promoting Social Inclusion of People with Dementia: Putting Social Citizenship into Practice is a community-based action research study striving to utilize the crucial perspectives of those people living with dementia in the community in order to combat the persistent stigma and social exclusion they face.

- Building Capacity Project

The 'Building Capacity' project is a cross-Canada partnership between researchers at the University of British Columbia and Lakehead University, and members of the Westside Seniors Hub in Vancouver and the North West Dementia Working Group in Thunder Bay. This four-year project is one of the first to launch under the Public Health Agency of Canada and its new, federally funded Dementia Community Investment strategy.

At its core, the 'Building Capacity' project aims to enable people living with dementia to participate in community life as full social citizens. The team uses a bottom-up, asset-based community development (ABCD) approach to support the growth of innovative community initiatives that will foster inclusion and reduce stigma by creating meaningful opportunities for people with dementia to remain active and socially connected.

- Citizenship across borders

Research Team: Alison Phinney, Gloria Puurveen, Deborah O'Connor, Lillian Hung, Susan Cox, and Lee Burnside.

Brings together researchers and community partners from UW and UBC to investigate how to effectively support social citizenship of people with dementia in the health care system and the community at large.

- The ideal Study

Research Team: Jennifer Baumbusch (PI), Alison Phinney, Deborah O'Connor, Paddy Rodney, Catherine Ward-Griffin

Project Description: The purpose of this study is to develop a better understanding of how care is negotiated in long-term residential care (LTRC) facilities. This is a 4-year critical ethnography that aims to generate a rich, contextualized understanding of the negotiation of care work in LTRC and to clarify factors (e.g. policies, best practices) needed to foster supportive collaborative relationships among families, residents and staff and improve the health and well-being of these groups. Specifically, this study will allow for an examination of the influence of socio-political and cultural contextual factors (e.g. Social locations: gender, class racialization; Organizational factors: healthcare funding, provincial policies, LTRC restructuring) on the negotiation of care work among residents, family members and staff.

Interim Report: IDEAL Site 1 Interim Report September 2015

- Making art for making place

Making Art for Making Place: The Effect of Visual Art in a Transitional Care Setting

Research Team: Alison Phinney (PI), Landon Mackenzie, Michael Wilson

Funder: UBC Hampton Fund Research Grant

Project description: Students from Emily Carr University created paintings for Yale Road Centre, a transitional care facility in Surrey, BC. We are conducting a focused ethnography, conducting observations and interviewing students, staff, and residents to learn more the benefits of the art for people with dementia.

There is growing interest internationally in the potential for visual art in health care facilities to promote healing and wellness for patients, but the evidence base is very limited. Therefore, the specific aims of this study are: (1) to explore how paintings contribute to place-making by providing orientation cues and opportunities for social and emotional engagement of residents; and (2) to understand how the process of creating these paintings can influence students' understanding of the social impact of their art.

- New frontiers in episodic memory training for persons with Alzheimers disease and mild cognitive impairment

Research Team: Jeff Small

Funder: CIHR

Investigates how a memory training program called “Spaced Retrieval” (SR) might be effectively applied in helping persons with Alzheimer’s disease or Mild Cognitive Impairment improve their recent memory and quality of life. Phase 2 CIHR grant project is in the data analysis stage.

- The use of mobile technology applications to improve communication between care staff and residents in long-term residential care facilities

Research Team: R. Wilson, J. Small, A. Mihailidis

Funder: CFN Health Technology Innovation operating grant (funded through the federal Networks of Centres of Excellence (NCE) program).

In long-term residential care (LTRC), many residents have cognitive impairments and/or do not speak English. These barriers make it difficult for them to communicate with care staff. Due to recent technological advances, a promising solution would be to pair mobile communication technology (e.g., tablet, smart phone) with mobile health communication Apps or “cApps”. For example, cApps that provide language translation or visual supports may enable care staff and residents to communicate more effectively. The purpose of this pilot study is to examine the current status of cApp availability in the app marketplace, survey use of cApps in LTRC practice, and generate recommendations for cApp features that would most effectively address communication challenges in LTRC. This project is in the data analysis stage. facilities.

COMPLETED

- Promoting Social Citizenship for People with Dementia through Community-Based Programming

Research Team: Alison Phinney (PI), Jennifer Baumbusch, Deborah O’Connor, Barbara Purves, Elizabeth Kelson

Funder: Alzheimer Society of Canada 2015-2017

Project Description: This is an ethnographic study with two purposes: (1) to understand how community programs help support social citizenship for people with dementia; (2) to evaluate different research methods for including the perspectives and opinions of people with dementia.

The aim of this research is to better understand how community-based programming can help people with dementia remain as active and engaged citizens. While this kind of programming is becoming more common, there has been almost no research examining its impact, especially from the perspective of participants themselves. We are studying two existing programs: a social recreation club for younger people with early

onset dementia, and an adult day program for frail older people, many of whom have dementia. Results of this research will support social citizenship of people with dementia by improving our ability to understand the potential benefits of community-based programming.

- The Use of Mobile Technology Applications to Improve Communication between Care Staff and Residents in Long-term Residential Care Facilities

Study Result 1: Wilson, R., & Small, J. (under review, 2018). Using Mobile Technology to Support Communication in Long-term Care: An Exploratory Concept Mapping Study. Poster for the 47th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG), October 2018, Vancouver, BC, Canada.

Study Result 2: Wilson, R., Cochrane, D., Mihailidis, A., & Small, J. (under review, 2018). Review and Evaluation of Mobile Applications to Support Communication in Long-term Care. Poster for the 47th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG), October 2018, Vancouver, BC, Canada.

Study Result 3: Wilson, R., Small, J., Cochrane, D., & Mihailidis, A. (ms in preparation). Review of Mobile Apps to Support Person-Centred Communication in Long-term Residential Care.

- Promoting Social Citizenship for People with Dementia through Community-Based Programming

Study Result 1: Kelson, E., Phinney, A. & Lowry, G. (2017). Social Citizenship, Public art and dementia: walking the urban waterfront with Paul's Club. *Cogent Arts and Humanities*, 4(1), 1354527.

Study Result 2: Phinney, A. Kelson, E., Baumbusch, J., O'Connor, D. & Purves, B. (2016). Walking in the neighbourhood: performing social citizenship in dementia. *Dementia*, 15, 381-394.

- Making Art for Making Place: The Effect of Visual Art in a Transitional Care Setting

Study Result : Phinney, A. (2016). Art on the walls: evidence for improving dementia care environment.

Result 2: Art on the walls

- Changes in Social Interaction and Everyday Activity in Dementia

Study Result : Phinney, A., Dahlke, S. & Purves, B. (2013). Shifting patterns of everyday activity in early dementia: Experiences of men and their families. *Journal of Family Nursing*, 19, 348-374.

Study Result 2: McDuff, J. & Phinney, A. (2015). Walking with meaning: subjective experiences of physical activity in dementia. *Global Qualitative Research in Nursing*, 1-9.

- Meaningful Activity from the Perspective of Persons with Dementia

Study Result 1: Phinney, A. & Moody, E. (2011). Leisure Connections: Benefits and challenges of participating in a social recreation group for people with early dementia. *Activities, Adaptation and Aging*. 35, 111-130.

Study Result 2

Phinney, A. (2014). As the body speaks: creative expression in dementia. In L-C. Hyden, H. Lindemann, & J. Brockmeier (Eds.). *Beyond loss. Dementia, identity, personhood*. pp. 120-134. New York: Oxford University Press.

- Community Support, Personhood and Dementia Care: Exploring the interface

Study Result 1

O'Connor, D., Phinney, A. & Hulko, W. (2010). Contextualizing the dementia experience: a unique case study exploring social location. *Journal of Aging Studies*, 24, 30-39.

- CIRCA BC: Community based research to customize a computer-based reminiscence program for BC seniors with dementia

Study Result 1

Purves, B., Phinney, A., Hulko, W., Puurveen, G., Astell, A. (2015). CIRCA-BC and the role of the computer as a third party in social interaction. *American Journal of Alzheimer's Disease and Other Dementias*. 30, 101-107.

FLIPPING STIGMA

An entire community reaps the benefits when various voices are heard and understood. As a member of a community, one should feel as though they have a seat at the table—especially when it comes to decision-making for matters directly effecting their own daily lives.

Visit the flipping stigma website at www.flippingstigma.com

About us

Reducing Stigma and Promoting Social Inclusion of People with Dementia: Putting Social Citizenship into Practice is a community-based action research study striving to utilize the crucial perspectives of those people living with dementia in the community in order to combat the persistent stigma and social exclusion they face.

Who better to design a research study and dig deeper into discussions surrounding dementia and the social exclusion and stigma which too often accompany it than those with the perspective of lived experience of such circumstance?

At the centre of our research team, guiding the direction of the research, is the action group, which is made up of people living in the community with personal, lived

experience of dementia. The action group members play a lead role in planning research, guiding team decisions on how analysis should take place, and offer first-hand perspectives and interpretations of collected data. Community partners and academic researchers are consulted throughout the project.

Throughout this four-year project, our action group met monthly to discuss issues around stigma and to share first-hand experiences of social exclusion and inclusion. These conversations shaped the objectives of this project and determined the direction of future data collection.

The sorts of data we collected included candid, round-table conversations within our action groups and other community stakeholders, data collected from focus groups and more formal interviews with other people living in the community with dementia, and data collected through arts-based methods of collection (observations of arts-based activities and alternate forms of communication—through visual art-making and participation). The focus of these conversations included addressing what social exclusion and stigma look like for people living with dementia, how it is perpetuated, and how we can tackle these issues.

End Goal

To be able to create a deeper and more refined understanding of what it means to live with dementia in the community and how policy-makers can work together with people living with dementia to create safer, more inclusive communities.

Monthly Quotes from the Action Group

The following quotes encapsulate some of the experience of the Action Group and their collective work towards the creation of the Toolkit and the Flipping Dementia Stigma Guide.

“I’m a human being and...I’ve got the whole package here...you’re just looking at one thing...” Sarah, AG Member

“I have this burning desire to... help our... whole group of people with any neuro cognitive disorders... in real ways that can make their life easier.” Myrna, AG Member

“What sets this project apart is that people living with dementia are up front and active – it is our voices about our experiences” Granville, AG Member

“...The experience of this group has assisted me...to...advocate for what I...believe in or what I see is important, and it's also helped me in other areas where I’m advocating as

well...The whole impact of dementia upon me...has made me become an advocate for others and for myself. So what I'm saying is, this group has really helped me...Build those advocacy skills..." Craig, AG Member

"I try and look at it...I've got this disease and I didn't ask for it but here it is and so maybe there's a message here...maybe I'm supposed to have this...as a role model for other people..." Sarah, AG Member

"When I left the last meeting I was just absolutely thrilled because I could see us... flipping stigma on its ear and turning it upside down and making it a comfortable place so dementia doesn't have to be a horror show..." Sarah, AG Member

BUILDING CAPACITY PROJECT

Building capacity for meaningful participation by people living with dementia

About this Project

The 'Building Capacity' project is a cross-Canada partnership between researchers at the University of British Columbia and Lakehead University, and members of the Westside Seniors Hub in Vancouver and the North West Dementia Working Group in Thunder Bay. This four-year project is one of the first to launch under the Public Health Agency of Canada and its new, federally funded Dementia Community Investment strategy.

At its core, the 'Building Capacity' project aims to enable people living with dementia to participate in community life as full social citizens. The team uses a bottom-up, asset-based community development (ABCD) approach to support the growth of innovative community initiatives that will foster inclusion and reduce stigma by creating meaningful opportunities for people with dementia to remain active and socially connected.

While the project engages two distinct communities in BC and Ontario, together these communities unite under three shared objectives:

Implement an ABCD approach to adapt and create community programs and services that are meaningful and inclusive for people with dementia.

Conduct a developmental evaluation that will allow the team to learn how to best support the growth and integration of programs and services that are meaningful and inclusive for people with dementia.

Disseminate learnings to increase awareness and to support communities in their efforts to create opportunities for meaningful participation by people with dementia.

The 'Building Capacity' project is not about community organizations developing a whole new set of separate programs and services for people with dementia. Rather, it is about figuring out a sustainable process for adapting and creating meaningful programs and services that are inclusive for people with dementia. We want more people with dementia to be active and participating in their community in a variety of ways, but more importantly, we want increased capacity in our communities so this kind of active participation can continue to grow and flourish.

Project Structure

The Vancouver site will be led by a partnership team of UBC researchers and members of the Westside Seniors Hub; the Thunder Bay site will be led by a partnership team of Lakehead researchers and members of the North West Dementia Working Group. While the two project sites will be focused on their local communities, there will be opportunities for knowledge exchange across the sites throughout the four years of the project.

There will be a central project secretariat located at UBC that will be responsible for the overall evaluation, integration, and dissemination of project findings. While this is a collaborative project from start to finish, we anticipate that community groups will hold primary responsibility for implementation with project support (e.g. information and communication resources, staff support, special event funding, etc.), and the researchers will hold primary responsibility for the evaluation component. There will be shared responsibility for dissemination (with significant project support).

Additional Resources

Here are several resources that you may find useful regarding programs and guidelines for persons with dementia during the COVID-19 Pandemic.

- Building capacity workshop report 2020-June 11
- BCRPA guidelines for restarting operations
- Tips and considerations for “getting outside safely” for persons with dementia and dementia-friendly programs: A three-pronged approach
- Trout Lake community centre information
- Resources for staying safe and connected during COVID

Resource links: Choose to move and Vancouver and BC Parks and Recreation

- Troute Lake community centre association

Find out how we are promoting informal activities in our community while we are formally unable to facilitate any through our centre

- Choose to move program

Lots of free resources and a newsletter to keep older adults active and connected while adhering to physical distancing requirements. Some care partners may enjoy participating in upcoming, virtual programs. This is a great way for them to be supported while at home

- Active aging society

Promoting connected, active lives that enable older adults to age in place

- BD Parks and recreation

Maps municipal recreation centre reopening considerations. Maybe informative for other community organizations and group-based programs

RESEARCH PARTICIPATION

Putting social citizenship into action

The aim of our community-based action research project is to reduce stigma and promote social inclusion for people living with dementia.

We are looking for volunteers who want to work alongside researchers to help create this positive change. If you are interested in being involved in this study, contact us for more information. People with lived experience of dementia are especially welcome.

This study is being co-lead by Jim Mann, Deborah O'Connor, and Alison Phinney.

If you are interested in volunteering or have any questions, please contact Alison Phinney at alison.phinney@ubc.ca or 604 822 7484

RESEARCH PARTNERS

Our research is supported by the Canadian Institutes of Health Research, the Alzheimer Society of Canada, and other funders.

We work in partnership with community and health-care organizations who share our commitment to improving understanding and care for people living with dementia.

- Canadian Centre for Elder Law

British Columbia Law Institute

The British Columbia Law Institute (BCLI) carries out scholarly research, writing and analysis for law reform, collaborating with government and other entities, and providing materials and support for outreach and public information. The Canadian Centre for Elder Law (CCEL) carries out similar work focused on issues of interest to older adult.

<https://www.bcli.org/ccel>

- Emily Carr Institute of Art + Design

Health Design Lab

The Health Design Lab uses participatory design methods to catalyze, support and amplify initiatives that address complex health challenges.

<https://research.ecuad.ca/healthdesignlab/>

- Public Guardian and Trustee of British Columbia

The Public Guardian and Trustee (PGT) is a corporation sole established under the Public Guardian and Trustee Act that exists in part to protect the legal, financial, personal and health care interests of adults who require assistance in decision making.

<https://www.trustee.bc.ca/Pages/default.aspx>

- Paul's Club

Paul's Club is a social and recreational day program for men and women living with Young Onset Dementia

<https://paulsclub.weebly.com>

- Alzheimer Society

The mission of the Alzheimer Society of Canada is to alleviate the personal and social consequences of Alzheimer's and related diseases and to promote the search for causes, treatments and a cure.

<https://alzheimer.ca/en>

- Canadian Institutes of Health Research

The Canadian Institutes of Health Research (CIHR) is Canada's federal funding agency for health research. Composed of 13 Institutes, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our health care system.

<https://cihr-irsc.gc.ca/e/193.html>

STUDENT CONNECTIONS AND JOB OPPORTUNITIES

Training and job opportunities

Graduate students interested in pursuing research in areas supported by the CRPD should contact individual researchers for further information.

CRPiD Student Connections

The CRPiD Student Connections is a supportive environment and forum for graduate students and postdoctoral fellows of all disciplines/fields of study, who share an interest in dementia and gerontological scholarship.

This group aims to be diverse and inclusive, with members from across the UBC community, as well as other universities. There is no cost to join. Meetings will have a hybrid format (in-person and virtual) and will take place the last Thursday of every month.

Becoming a member of the CRPiD Student Connections will include:

Being a part of the greater CRPiD community

- Learn about and attend CRPD events and colloquiums
- Increase understanding of the dementia experience
- Learn from people living with dementia

Opportunities for expanding connections with other students

- Networking and socialization
- Meet others with similar research interests
- Connect across disciplines

Mentorship and learning from one another

- Support one another as new and developing scholars
- Find a mentee/be a mentor to others
- Share experiences as students/learn from one another

Encouragement and feedback on scholarly work

- Join or form a writing group
- Tips on publishing and writing grants
- Practice presentations and thesis defences in front of peers
- Discuss and explore different research methods

If you would like to join, please email Sheila Novek at sheila.novek@ubc.ca

KNOWLEDGE APPLICATION

PUBLICATIONS

- O'Connor, D. (2020) Practicing social citizenship in a context of compromised decision-making capacity: Realizing and Protecting Human Rights. *Elder Law Review* 12 PDF
- O'Connor, D., Mann, J., & Wiersma, E. (2018) Stigma, Discrimination and Agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging studies*, 44, 45 – 51
- Wiersma, E., O'Connor, D, Loiselle, L., Hickman, K. Heibein, B., Hounam, B. & Mann, J. (2016) Creating Space for Citizenship: The Impact of Group Structure on Validating the Voices of People with Dementia *Dementia: International Journal of social research and practice* 15(3).
- Small, J. Hulko, W., O'Connor, D. & Drance, E. (2016) Verbal and nonverbal indicators of quality of communication between care staff and residents in ethnoculturally and linguistically diverse long-term care settings, *Journal of Cross-Cultural Gerontology*.
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- Phinney, A., Chaudhury, H., O'Connor, D. (2007) Doing as much as I can: Exploring meaningful activity in dementia. *Aging and Mental Health*. 11(4), 384 – 393.
- O'Connor, D. (2007) Developing a caregiver identity: the positioning process. *Journal of Aging Studies*. 21 , 165-174
- Bartlett, R. L. & O'Connor, D. (2007) From Personhood to Citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies* 21, 107 – 118.

Non Refereed Government-contracted reports

- O'Connor, D. (2020) Incapability Assessments: A review of Assessment and Screening Tools (Revised and updated) Report commissioned by the Public Guardian and Trustee's Office. (Report is complete but not yet available to public)
- O'Connor, D. (2009) Incapability Assessments: A review of Assessment and Screening Tools. Report commissioned by the Public Guardian and Trustee's Office. PDF
- Hung, L., Son, C., & Hung, R. (2018). The experience of hospital staff in applying the Gentle Persuasive Approaches to dementia care. *Journal of psychiatric and mental health nursing*.
- Sakamoto, M. L., Moore, S. L., & Johnson, S. T. (2017). "I'm Still Here": Personhood and the early-onset dementia experience. *Journal of Gerontological Nursing*, 43(5), 12-17.
- Kelson, E., Phinney, A. & Lowry, G. (2017). Social citizenship, public art and dementia: walking the urban waterfront with Paul's Club. *Cogent Arts and Humanities*, 4(1), 1354527.
- Phinney, A. Kelson, E., Baumbusch, J., O'Connor, D. & Purves, B. (2016). Walking in the neighbourhood: performing social citizenship in dementia. *Dementia*, 15, 381-394.
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- Purves, B. & Phinney, A. (2013) Family voices: a family systems approach to understanding communication in dementia. *Canadian Journal of Speech Language Pathology and Audiology*, 36, 284-300.
- O'Connor, D., Phinney, A. & Hulko, W. (2010). Contextualizing the dementia experience: a unique case study exploring social location. *Journal of Aging Studies*, 24, 30-39.
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Books

- *Broadening the Dementia Debate: Towards social citizenship*. Authors: Ruth Bartlett and Deborah O'Connor
- *Remembering Home: Rediscovering the Self in Dementia*. Author: Habib Chaudhury

Book Chapters

- Phinney, A. (2018). Self, Lost and Found. In P. Tortell, M. Turin, & M. Young (Eds). *Memory*. pp. 243-250. UBC Press.
- Phinney, A. (2014). As the body speaks: creative expression in dementia. In L-C. Hyden, H. Lindemann, & J. Brockmeier (Eds.). *Beyond loss. Dementia, identity, personhood*. pp. 120-134. New York: Oxford University Press.
- Purves, B., Savundranayagam, M., Kelson, E., Astell, A. & Phinney, A. (2011). Fostering resilience in dementia through narratives: Contributions of multimedia technology. In: B. Resnick, L. Gwyther, & K. Roberto (Eds.). *Resilience in aging: Concepts, research, and outcomes*. 231-243. New York: Springer.

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Selected Presentations

- Phinney, A. (2015). Making art for making place: Imagining possibilities in dementia. Paper presentation. From Memory Loss to Memory Shift: Rethinking the Discourse of Pathology, University of Toronto, September 26. Watch the conference presentation [here](#)
- Wilson, R., Amtmann, D., Small, J. & Mihailidis, A. (2015, October). Using Mobile Communication Technology to Improve Social Participation in Frail Elderly Residing in Long-term Care: An Exploratory Group Concept Mapping Study. Poster presentation at International Society for Quality of Life Research (ISOQOL), Vancouver, BC, Canada.
- Small, J.A. Spaced Retrieval: A User-friendly Cognitive Rehabilitation Strategy for Persons with Dementia. Workshop presented at the 24th Scientific Meeting of the Canadian Academy of Geriatric Psychiatry, Vancouver, B.C., September 30, 2015.

EDUCATIONAL SERIES

- Video: Covid-19 and family perspectives on living well with dementia (watch on [website](#))
- Video: Programming without walls (watch on [website](#))

MULTIMEDIA

- In here out there, Art making space to live well with dementia

This art exhibition is part of a larger research project that focuses on learning from people living with dementia and their care partners about what it means to live well with dementia to the end of life, including plans for future health and social care.

Visit website: www.artmakingspace.com

- Flipping stigma on its ear toolkit for addressing stigma

The purpose of this toolkit is to recognize and respond to stigma and discrimination. It has been designed by people with dementia to help others - including other people living with dementia, service providers, physicians, family members and friends - to address the challenges of stigma and discrimination.

Visit website: www.flippingstigma.com

NEWS AND EVENTS

UPCOMING EVENTS

Stay tuned for the next events.

PAST EVENTS

February 14, 2024

COLLOQUIUM SERIES

Exploring the Power of Dance to Support Embodied and Relational Capabilities

Pia Kontos talks about decreasing stigma associated with dementia and fostering dementia-inclusive communities are key public health priorities across national and international settings. The analysis presented, draw on a relational model of citizenship, highlighted the critical role of embodiment in creative self-expression and social engagement and also highlighted broader issues of inclusivity and the imperative to more fully support engagement with the arts for human flourishing.

February 13, 2024

COLLOQUIUM SERIES

UBC Healthy Aging Research Seminar

Fostering Aesthetic Engagement through Filmed Research-based Theatre: An Arts-based Approach to Culture Change in Dementia Care

This session featured a screening of "Cracked: New Light on Dementia", a film intended to inspire alternative ways of seeing persons living with dementia and to foster a culture of care that supports people to live well with dementia, followed by a Q& A session with Dr. Kontos.

September 27, 2023

COLLOQUIUM SERIES

The Role of Neighbourhood Built Environment on Outdoor Mobility of People Living with Dementia

Dr. Habib Chadhury, PHD candidate Kishore Seetharaman and MA candidate Cari Randa-Beaulieu talk about the "Dementia-inclusive Spaces for Community Access, Participation, and Engagement (DemSCAPE)". This study aims to identify spatial and temporal patterns in activities undertaken outside home by people living with dementia, and ways in which the neighbourhood built-environment affects their outdoor mobility and social participation.

June 12, 2023

COLLOQUIUM SERIES

Raising the curtain on the lived experience of dementia

Dr. Julia Henderson and Dr. Colleen Reid talk about their research "Raising the Curtain". A community-based participatory research (CPBR) project that explores the question: "What is the lived experience of dementia?" through the ideas, creativity and perspectives of those living it.

May 23, 2023

COLLOQUIUM SERIES

Social Prescribing: Healthcare-Community Collaboration to Support Quality of Life

Margaret Lin discusses how BC is implementing social prescribing, how social prescribing can support a person's autonomy and quality of life, the potential for social prescribing to become a valuable resource for people living with dementia, their care partners, and healthcare providers, and how you can actively support this effort.

December 6, 2022

COLLOQUIUM SERIES

Digital Learning and Remotely Supervised Online Chair Yoga: For Rural and Underserved Adults at Risk of Cognitive Impairment

Dr. Park and her research team have conducted a randomized control trial to test the feasibility of an online chair yoga intervention for rural older adults at risk for cognitive impairment in an underserved, racially/ethnically diverse community. Outcomes from the project are reported in this presentation.

November 14, 2022

COLLOQUIUM SERIES

Understanding Service Engagement and Resistance among People Living with Young Onset Dementia and Family Members

Dr. Sheila Novek shares her dissertation research exploring the complex processes that impact dementia care access, drawing on in-depth interviews with people living with the young onset dementia, family members and providers in Winnipeg, Manitoba.

September 20, 2022

COLLOQUIUM SERIES

Fostering Intergenerational Connection: Perceptions & Projections

Dr. Shelley Canning discusses work she has been doing with school-aged children, fostering intergenerational connection, addressing ageism, and improving knowledge of dementia amongst younger people.

May 25, 2022

COLLOQUIUM SERIES

Working in Partnership with People Living with Dementia: Examples from UK
Community Based Initiatives and Research
Dr. Anthea Innes

April 26, 2022

COLLOQUIUM SERIES

Peer Mentorship and Dementia: Possibilities for Post-Diagnostic Support
Dr Laura Booi, a Gerontologist and Research Fellow at Leeds Beckett University's
Centre for Dementia Research in the United Kingdom, discusses the developments of a
project, funded by a UK Research and Innovation Catalyst Award, to co-develop a peer
mentorship program with people living with Lewy Body Disease.

March 17, 2022

COLLOQUIUM SERIES

Engaging People Living with Dementia in Decision Making
Speakers Krista James and Jess Fehrenbacher discussed the legal rights relating to
decision-making for people living with dementia, and shared insights from the
community on supported decision-making, along with tools that were created to support
decision-making. Community member Jerry Gosling also shared his perspectives.

January 25, 2022

COLLOQUIUM SERIES

ADDRESSING STIGMA AND DISCRIMINATION: Hearing the Voices of People with
Dementia
Led by Alison Phinney, Jim Mann, Debora O'Connor and Members of the Action Group

December 6, 2021

COLLOQUIUM

CO-LEADING RESEARCH TOGETHER: The Telepresence Project
Dr. Lillian Hung and LL.D Jim Mann

September 22, 2021

COLLOQUIUM

DEMENTIA ALLIANCE INTERNATIONAL, The Global Voice of Dementia
Emily Ong. Raising awareness on Dementia Issues and actions needed.

April 3, 2019

COLLOQUIUM

Dr. Hildur Kalman, a physiotherapist and Professor of Social Work from Umeå
universitet in Sweden presented her recent research that has been focused on

observing and understanding how intimate care is provided to older adults in their own home.

March 8, 2019

Gloria Puurveen, Alison Phinney, and Lee Burnside gave a presentation at the Discovery 2019 Alzheimer's Regional Conference hosted by the Alzheimer's Association in Seattle, Washington. Their talk was entitled "A New Vision of Social Citizenship for Communities and People Living with Memory Loss".

Their workshop explored how to create sustainable dementia-friendly communities and how to engage people with dementia in planning community initiatives. It also covered the use of art as a way for someone to express their desires and discussion about what "dementia friendly" means to the person with memory loss.

February 27, 2019

COLLOQUIUM

Rapid-fire presentation event was organized and hosted by the Center for Research on Personhood in Dementia. It featured research participants, advisors, practitioners, researchers, and students who shared stories about their involvement in dementia research, as well as their current research initiatives.

January 18, 2019

MEMORIAL FOR DR. MARTHA DONNELLY

It is with a sense of profound sadness and shock that we are sharing the news that Dr. Martha Donnelly died suddenly on January 10, 2019.

Martha was a significant and tireless advocate and pioneer in geriatric mental health and dementia care. She provided leadership – and friendship – to many of us in the geriatric mental healthcare communities in BC and across Canada.

Martha was also founding member of the Centre for Research on Personhood and Dementia (CRPD).

It is difficult to name all of the committees and expert panels that Martha participated on – always bringing a candid, informed lens that pushed for best care for older Adults. Her advocacy, ability to work as a team member and expertise helped to inform the framework of the Adult Guardianship Act of BC, push for a National Dementia Framework, and develop many 'best practices' related to assessing incapability, family care and dementia care.

Martha will be missed for her energy, dedication, knowledge and empathy that she had for those who were more vulnerable and for those of us who were privileged to work with her at some point during her busy and impressive career.

December 10, 2018

Dr. Alison Phinney read from her essay “Self, Lost and Found” recently published by the Peter Wall Institute of Advanced Studies, that explores how perspectives of care might change the way we think about memory loss at the end of life. This public reading was sponsored by the Vancouver Public Library as part of their year long morph exhibition.

November 13, 2018

Dr. Daryl Pullman, Professor of Medical Ethics at Memorial University of Newfoundland, gave a lecture on the subject of medical assistance in dying, and the role of women in shaping Canadian policy in this area.

April 11, 2018

David Lemon, Founder and Executive Director of the Health Arts Society spoke about the Helena Choir – Considering Evidence in Music and Dementia Programs. This was followed by a lively panel discussion with Susan Cox (UBC Centre for Applied Ethics), Shelley Canning and Darren Blakenborough (University of the Fraser Valley School Centre for Education and Research on Aging), and Rena Sharon (UBC School of Music).

October 12, 2017

COLLOQUIUM

Sylvie Fourcin, the director of Artlink, a community arts and health organization in Leeds, presented an ethnographic evaluation of their three-year program of participatory arts work with adults with learning and physical disabilities, mental health issues and dementia who attend day centres.

July 12, 2017

COLLOQUIUM

Emily de la Cruz Ellis, a Master of Design graduate from Emily Carr University of Art + Design, and Carolyn Kerchof a Master of Arts in Design graduate of Zurich University of the Arts discussed principles of inclusive communication design and how these have been applied in creative and thoughtful ways using examples from their research with older people including those with dementia.

June 26, 2017

COLLOQUIUM

Riley Malvern, Master’s candidate in Gerontology at Simon Fraser University, discussed her proposed research “Facilitators and Barriers of the Neighbourhood Built Environment for People in Early-Stage Dementia”.

May 23, 2017

COLLOQUIUM

Dr. Christine FitzGerald, a visiting scholar from the Global Brain Health Institute at Trinity College Dublin and the Centre of Social and Economic Research on Dementia at NUI Galway discussed her research to develop an “Expanded Psychosocial Classification Framework”.

May 2, 2017

COLLOQUIUM

Niamh Hennelly, a PHD student visiting from the Irish Centre for Social Gerontology at NUI Galway, spoke on the topic of “Personhood in Policy: An Analysis of the Irish National Dementia Strategy”.

2017

USING IPADS TO HELP HOSPITAL PATIENTS WITH DEMENTIA

Doctoral Student Lillian Hung was interviewed on CBC Radio about her project exploring the use of iPads to share pre-recorded videos made by families to help comfort people with dementia while hospitalized. Listen to the full interview [HERE](#).

BLOG

Read the blog online.

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ACCESSIBILITY STATEMENT

The CRPiD is committed to providing a website that is accessible to the widest possible audience, regardless of circumstance and ability. We aim to adhere as closely as possible to the Web Content Accessibility Guidelines (WCAG 2.0, Level AA), published

by the World Wide Web Consortium (W3C). These guidelines explain how to make Web content more accessible for people with disabilities. Conformance with these guidelines will help make the web more user friendly to everyone. Whilst the CRPiD strive to adhere to the guidelines and standards for accessibility, it is not always possible to do so in all areas of the website and we are currently working to achieve this. Be aware that due to the dynamic nature of the website, minor issues may occasionally occur as it is updated regularly. We are continually seeking out solutions that will bring all areas of the site up to the same level of overall web accessibility.

If you have any comments and or suggestions relating to improving the accessibility of our site, please don't hesitate to contact us at samantha.pineda@ubc.ca. Your feedback will help us make improvements.