

CENTRE FOR INCLUSION AND CITIZENSHIP

The Centre for Inclusion and Citizenship is a partnership between the UBC School of Social Work, community living organizations and supporters which seek to further the inclusion and full citizenship of people with intellectual disabilities and their families locally, nationally and globally. The Centre seeks to contribute to this goal through learning, research, and knowledge exchange.

We believe in...

▪ Inclusion

We all have a responsibility to create inclusive and welcoming communities

▪ Citizenship

Being a citizen means enjoying all the rights and responsibilities that most people take for granted

▪ Access

Everyone needs and has a right ~ to live in a safe and comfortable place that they can call home ~ to engage in meaningful work for fair pay ~ to enjoy reciprocal relationships ~ to have access to public facilities ~ and to live a full life in the community

▪ Lifelong Learning

We are committed to fostering, supporting, and maintaining a culture of lifelong learning to support growth, innovation and excellence

▪ Leadership

Achieving truly inclusive and welcoming communities for all citizens requires leadership by everyone. We are committed to demonstrating, supporting and developing leadership

▪ Collaborative Practice

We believe innovative solutions to the issues faced by people with intellectual disabilities will be found in new relationships and partnerships

Message from the Director



For the first time in the short life of the Centre, I can honestly say I am optimistic about both its future and its impact. While we have had many successes to date, it has been a constant struggle to maintain the Centre's core infrastructure and maintain our programmes and visibility. With new initiatives and new funding on the horizon, it feels as if we are turning the corner from infancy to at least adolescence!

The successful launch of both the annual *Research With Relevance* day and the *Ideas Workshops Series* did much to help us fulfil our mandate to bring in new ideas and stimulate discussion in our community. The *Canadian Inclusive Lives Learning Initiative*, CILLI, has had a successful second season and there are very positive signs for its development and growth in the coming years where we hope to make it more broadly accessible across the province.

On the research front, we are presently wrapping up some important projects and beginning exciting new initiatives. This work not only produces important information for the sector and the community at large, but also provides opportunities to bring in new researchers to the field and give students an opportunity to learn about community living while developing new skills.

Moving forward, there are a number of new or under developed areas we would like to work on in the coming year. These include, increasing our focus on children and their families, increasing our partnerships with other academic and community bodies, improving the effectiveness of communicating our work to self advocates and, making the Centre and its programmes and information more broadly available. On this last issue, we are thrilled to learn that UBC Okanagan, where Centre Co-Director Dr. Rachele Hole is based, has agreed to provide newly renovated space to the Centre, which will allow Dr. Hole and her team to continue and expand the critical work they do on behalf of the Centre. As always, despite some improvements, we need to continue to seek resources to support the ongoing work of the Centre and ensure its ongoing viability.

The work of the Centre takes many hands and I would like to acknowledge our board members, funders, research affiliates, student interns and research assistants, the School of Social Work staff and all our community and government partners for the enormous contributions they make to our work. I want to particularly acknowledge Meaghan Feduck, CIC project officer, for her many contributions to the Centre and particularly her outstanding work on the CILLI programme. And lastly, a special thanks to Cindy Chapman, the centre coordinator, without whose dedication and tireless efforts the Centre would not be as successful as it is.

— Dr. Tim Stainton

About the Centre

The Centre for Inclusion and Citizenship, at the UBC School of Social Work, was established through a partnership of University, government and community living organizations and supporters seeking to further the inclusion and full citizenship of people with intellectual disabilities and their families locally, nationally and globally. More specifically, the Centre was created to meet an identified need to conduct research to influence and inform policy and practice and to translate that knowledge into best practices.

2012-2013 Provincial Advisory Board Members

Angela Clancy, Family Support Institute

Angie Kwok (past), BC Centre for Ability

Brian Salisbury, Community Living British Columbia

Dan Collins (Chair), Langley Association for Community Living

Faith Bodnar, Inclusion BC (formerly BC Association for Community Living)

Gordon Fletcher (past), Self Advocate Consultant

Janice Barr, Richmond Society for Community Living

Jerry Laidlaw, Self Advocate Consultant

Kathleen Haggith, Kwantlen Polytechnic University

Laney Bryenton, Elan Consulting

Michael McLellan, Self Advocate Consultant

Michael Prince, University of Victoria

Molly Harrington, Ministry of Social Development

Rachelle Hole, University of British Columbia

Tim Stainton, University of British Columbia

“I was happy to join the board. I believe it is important for self advocates to be involved in all aspects of research and help share the information with other community members.”

— Michael McLellan

Built from the grassroots as an innovative and collaborative solution to quench an ongoing thirst for knowledge and desire to improve the lives of children and youth with special needs, adults with intellectual disabilities and their families in BC, the CIC is one of a kind.



Studentship Awards

The 2012-2013 CLBC Studentships were awarded to Courtenay Dennis, UBC-O and Sandy Rogers, UBC-Vancouver. With the support of Community Living British Columbia, the Centre offers studentships for BSW and MSW level students at UBC wishing to explore career opportunities in the field of intellectual disability. The awards encourage students to consider a career in community living upon completion of their degree and support the development of professionals with both commitment to, and expertise in, fostering the inclusion and citizenship of people with intellectual disabilities in British Columbia. Students complete their work experience at CLBC and contribute additional hours working with the Centre.



Learning

Canadian Inclusive Lives Learning Initiative



The Centre's pilot initiative has seen some exciting advancements in 2012-2013. CILLI is a learning program designed by and for people with disabilities and their family members. The nine-month program consists of two in-person retreats, eight online modules, and monthly expert sessions delivered through teleconference meetings. Participants join a cohort of twenty learners to build inclusive lives in their communities.

In June 2012, the first cohort of participants wrapped up the course at a weekend retreat. Having tested the curriculum and received feedback from participants in 2011-2012, the CIC undertook an evaluation and upgraded the content and delivery mechanisms of the course. A second cycle of the course was offered in September.

The Centre has learned the value that CILLI offers to participants. Some of this value lies in having completed the course and received a certificate; some lies in the social connections made; and some lies in the increased leadership gained through presentations, workshops, and media interviews.

Future development of this unique curriculum will focus on building partnerships with post-secondary and other organizations to jointly deliver the course throughout various locations in British Columbia.

We wish to thank our supporters, content experts, course development and participant sponsors.

Content Experts:

- Linda Perry, Executive Director, Vela Microboard Association of BC
- Si Stainton, Family Services Manager, Delta Community Living Society
- Aaron Johannes, Director of Research, Training and Development, Spectrum Society for Community Living
- Chris Arnold, Clinical Director, Provincial Networking Group Inc.
- Jack Styan, VP, Strategic Initiatives, Community Living BC
- Kathleen Haggith, Dean, Academic and Career Advancement, Kwantlen Polytechnic University
- Cindy Chapman, Coordinator, Centre for Inclusion and Citizenship
- Tamara Kulusic, Manager of Policy and Program Development, Community Living BC



Graduate Student Research

Dr. Hole and Dr. Stainton have been pleased to support the following graduate students at the University of British Columbia, University of Victoria and Simon Fraser University this year.

- Assunta Rosal (Master of Social Work) - *Parents' perspectives of youth transitioning to adulthood and residential options that promote inclusion*
- Beth Devolder (Interdisciplinary Graduate Studies Program PhD) - *Exposing Disabling Discourses*
- Catriona Johnson (PhD University of Victoria) - *Shared Resources and Collective Decision-Making: Family Governance as a Model of Support for Individuals with Developmental Disabilities*
- Donna Good Water (Interdisciplinary Graduate Studies Program PhD) - *Suknaquinx Knowledge and Intellectual Disability*
- Earllene Roberts (Interdisciplinary Graduate Studies Program PhD) - *University discursive practices and student subjectivity: Privileging ability*
- Jewelles Smith (Interdisciplinary Graduate Studies Program PhD) - *Intergenerational effects of institutionalization in the lives of individuals with disabilities*
- Meaghan Feduck (Master of Social Work) - *It's about time: the significance of the centre block demolition for former residents of the Woodlands institution*
- Pat Feindel (PhD - Simon Fraser University) - *Memory and Visibility: Speaking Through the Woodlands Memorial Garden*
- Peter Speers (Interdisciplinary Graduate Studies Program PhD) - *Physical Fitness and Intellectual Disability: A Grounded Research Study*
- Sevinj Asgarova (PhD Social Work) - *Parents experiences of pre-natal testing and intellectual disabilities*
- Valerie Millar (Interdisciplinary Graduate Studies Program PhD) - *Representations of Disabled Women in Canadian Literature*
- Jill Mitchell (Interdisciplinary Graduate Studies Program MA) - *Disability and Discourses of Genocide*

UBC School of Social Work Student Practice Conference

The Centre was pleased to share our work with social work students during an annual conference at UBC on January 4th. Students interested in research and practice in the field of Community Living engaged in a session focused on sharing the research, community development, and educational opportunities offered through the Centre.



“Thanks to the Centre for Inclusion and Citizenship, I’ve had a great opportunity to have a practicum placement with Community Living BC, where I worked directly with individuals and families. In this placement I had a great opportunity to meet some amazing people. The work study research position with Dr. Rachele Hole was related to the wellbeing of people with intellectual disabilities. I was transcribing interviews from people all over the province, documenting their experiences and ideas for the future. This position was not just work for me; it provided me with the chance to learn in a way where I wasn’t being tested on the material I had learned, and instead allowed me to absorb the information without being taunted by a final exam. This was an excellent opportunity for my own professional growth as well as a great way to connect and network with key members of the community. It has also allowed me to grow as a person and to begin to raise awareness in my own social circles about the experience that people with intellectual disabilities face, and to spread the word about inclusion. Now that I have experience seeing both sides of the coin I think that I have a deeper understanding of the relationships between CLBC and the people that they provide support to. I have heard the experiences of families, self advocates and community members and I have also seen the great work that CLBC does. I feel confident that it will allow me to make better informed decisions and make my work very much person-centered in my future career.”

— Courtenay Dennis,
BSW Student UBC-O

Message from the Chair



It has been a privilege to participate in the creation and development of the Centre for Inclusion and Citizenship and I share Tim's optimism for its future. I am thankful for the patience and perseverance of all those involved who have maintained a belief in its potential and worked consistently to demonstrate the value of a concentration on research and knowledge exchange. Throughout the annual report, you will see firsthand the growth and reach the Centre has achieved in its few short years of operation.

The Centre is unique for a number of reasons, but most importantly in its desire to engage a variety of stakeholders in its work. Individuals and families, government funders and policy makers, academics from a variety of disciplines and service providers are all able to actively engage in the creation of the research agenda and participate in knowledge exchange. It is in this co-creation that our work can have a positive impact on future developments pertaining to intellectual disability.

New ideas for research, information sharing and knowledge exchange are always emerging. British Columbia is frequently cited for its capacity to innovate and bring new ideas to scale. The Centre wants to play a central role in informing policy and practice to be sure, but our challenge at the present time is to temper this desire with the fiscal realities we currently face. It has been a struggle to maintain core infrastructure and I must acknowledge the incredible support we have received from the UBC School of Social Work. I want to encourage you to keep connected to us and welcome any input you may offer that strengthens our sustainability.

Lastly, I want to acknowledge the support and contribution of the members of the Centre's provincial advisory board. The advisory board members bring a wonderful diversity of knowledge and experience and their wisdom and guidance are invaluable in shaping the ongoing work of the Centre. They share a common vision for the Centre and have remained positive and optimistic as the Centre has found its legs. I believe that we have a bright and prosperous future.

— Dan Collins



Professional Development, Community Presence and Engagement

This past year has seen a very strong increase in our knowledge exchange activities. The Centre has been involved in a number of activities that have strategically positioned us for continued growth and success.

Our reach outside the community living movement continues to expand as we have hosted events and dialogues, have been fortunate to talk with new and potential partners, and share our work by presenting at professional and academic conferences and publishing research finding in academic journals.

Research with Relevance, May 2012

Our first Research with Relevance day, designed to engage, inform and inspire and really talk about the importance of research in our sector, was a great success. We sincerely appreciated the input we received from participants and hope this day will become an annual event where we can exchange knowledge and create opportunities to promote full inclusion and citizenship.

Communicating in Plain Language

As we work to improve the ways we share and communicate our work in plain language, we'd especially like to acknowledge the expertise and leadership provided by Barb Goode and Leah Wilson who have been working with the Centre as consultants in this area. Our work in 2013 includes creating a plain language strategy for knowledge translation.

Historical Collections and Archives Project

Recently, the importance of preserving the history of this movement has become a critical priority for understanding and recognizing the power of community living as a social justice movement, and to maintain its strength into the future. The CIC has begun to explore a project to develop ways to preserve information, data, documents and artifacts of historical value to the community living movement.

The research project will draw on the assets of a working group made up of movement leaders, educational professionals, and community developers. The end goal is a collection of materials that can be used by researchers, organizations, advocates and community initiatives to advance the inclusion of all citizens. This project is currently under development and is seeking funding partnerships.

“As we look to future research projects in the area of employment and disability, we have had the opportunity to meet with members of the BC Centre for Employment Excellence to talk about areas of shared interest and possible collaborations. We've appreciated the opportunities to connect with this committed team of people; the possibilities of partnering around shared work is very exciting.”

— Rachelle Hole



On the series, overall...

“I appreciated every speaker and each person’s unique contributions. Thoughtful, hopeful and powerful ideas for moving forward.”

Understanding our Past

“I came thinking it would be somewhat redundant but leave knowing I needed to revisit it and hear it again. It reminded me to remember and know.”

“What resonated most for me was a history that is profound – and needed repeating even for those of us who think we know it.”

Creating Community

“What the day did was give me a new passion to connect with my own community. It also gave me the tools to take what I learned and apply it to my work.”

“Absolutely loved the session with Pilar Riano-Alcala. Specifically notion of ‘Capacity to aspire’.”

How to Engage Community

“‘Gifts are not gifts until they are given’ - loved that. The power of invitation.”

2012–2013 Community Living Ideas Workshop Series

This year, the Centre launched a series of four ideas workshops as part of our commitment to offer educational experiences and professional development opportunities to promote a deeper dialogue around contemporary issues facing community living.

The workshops engaged community members in debate and reflection on where we, as a community living movement have come from, and what philosophies and ideas could or should underpin the community living movement going forward.

The workshops were designed to build upon each but participants were invited to attend all or any of the series. The 4 day-long workshops were offered at 6 week intervals October 2012 through February 2013 at the Vancouver Public Library Square and Conference Centre in downtown Vancouver.

In addition, we were fortunate to partner with posAbilities and Community Living BC to present a second full day building upon the Creating Community workshop.

Approximately 325 people attended the five workshops and momentum did build throughout the series. We believe the series contributed to us building our profile, increasing our visibility and expanding our reach with a variety of partners.

1. **Understanding Our Past** -OCTOBER 15, 2012
2. **Creating Community** -NOVEMBER 26, 2012
How to Engage Community: Starting New Conversations with Neighbours -NOVEMBER 27, 2012
3. **Securing Our Rights** -JANUARY 21, 2013
4. **Defining Our Future** -FEBRUARY 25, 2013

Workshop descriptions and presentations are available on the CIC website.



Presentations

- Presentation on Centre for Inclusion and Citizenship Current Research, SSHRC Disability Policy Network. May 2012. Presenter: Tim Stainton
- Home Sharing: Exploring the experiences of self-advocates, family members, and home share providers. BC Association for Community Living Conference. Penticton, BC. May 2012. Presenter: Rachelle Hole
- Individualized Funding Cost and Service Utilization Research Report. CIC Research with Relevance Day. Penticton, May 2012. Presenter: Tim Stainton
- Rights Based Social Care: Policy And Practice Models. Hong Kong University. June 2012. Presenter: Tim Stainton
- Research with person whose mental capacity is diminished. Hong Kong University, June 2012. Presenter: Tim Stainton
- Rights Based Social Care: Policy And Practice Models. Shandong University, June 2012. Presenter: Tim Stainton
- Reason's Other: The History of Intellectual Disability from the Classical to the Early Modern. Understanding Our Past Workshop, Centre for Inclusion and Citizenship, Vancouver, BC. October 2012. Presenter: Tim Stainton
- Panel Discussion on Assisted Suicide and Pre-natal Testing. Canadian Association for Community Living Conference. Winnipeg, MB. October 2012. Presenter: Tim Stainton
- Presentation on Home Sharing Project Findings. Community Living British Columbia .September 2012. Presenter: Rachelle Hole
- Home Sharing: Info for Families and Self-Advocates. Family Focus Conference. Burnaby, BC. October 2012. Presenter: Rachelle Hole
- Home Sharing for adults with intellectual disabilities: A qualitative exploration. Qualitative Health Research, Montreal, QC. October 2012. Presenter: Rachelle Hole
- Uncharted territory: Health and Social Services for Older Adults with Intellectual Disabilities. Canadian Association on Gerontology, Vancouver, BC. October 2012. Presenter: Jennifer Baumbusch
- "There is a hell on earth": Institutions for persons with intellectual disabilities. Conference comparing the institutionalization of persons with disabilities and residential schools. Kwantlen Polytechnic University. November 2012. Presenter: Tim Stainton
- Rights in Policy and Practice. Securing Our Rights Workshop, Centre for Inclusion and Citizenship. Vancouver, BC. January 2013. Presenter: Tim Stainton
- Into or out of the Future? Selective Abortion, Assisted Suicide and Euthanasia. Defining Our Future Workshop, Centre for Inclusion and Citizenship. Vancouver, BC. February 2013. Presenter: Tim Stainton

Publications

Hole, Rachelle, Stainton, T., & Wilson, L[1]. Ageing adults with intellectual disabilities: Future hopes and concerns of self-advocates and family member experiences. Australian Social Work. Published by Taylor & Francis

Hole, R., *Nunn, N., *DeVolder, B., & Berg, L. (March 2012). Western Canada Case Study Research Project - Supports and Accommodations for Disabled People with Intermittent Work Capacity in Two Organizations in the Okanagan Valley. Human Resource & Skill Development Canada, Office of Disability Issues, May 2012. 63 Pages.

Hole, R., Stainton, T., Robinson, C., Crawford, C., & Lige, S. (2012). Home sharing: A study of resident and stakeholder views. Journal of Intellectual Disability Research, 56 (7-8), 781.

Stainton, Tim & Clare, Isabel C. H.(2012). Editor, Special Issue on Human Rights and Intellectual Disability, Journal of Intellectual Disability Research. V. 56- No. 11.

Stainton, Tim & Clare, Isabel C. H.(2012). Editorial, 'Human rights and intellectual disabilities: an emergent theoretical paradigm?'. Journal of Intellectual Disability Research. V. 56- No. 11. pp. 1365-2788.

Stainton, Tim (2012) 'Empowerment and the architecture of rights based social policy'. In Johannes A. (ed.) From Institutions to Individuals: on becoming person centred. Vancouver: Spectrum Press. p.p. 89-99. (Reprint of 2007 article in British Journal of Intellectual Disabilities).

Watson, S., Stainton, T & Sobsey, D. (2012) A Right to Exist and to Life-sustaining Measures . D. Griffiths, F. Owens & S. Watson (Ed) In The Human Rights Agenda For Persons With and Intellectual Disabilities. New York: NADD Press. Pp.19-37.

2012 – 2013 Ideas Workshop Series

Thank you to this year's presenters:

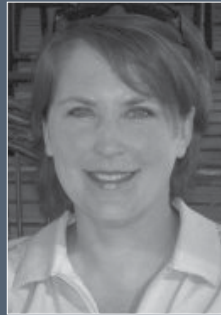
- Aimee Quaife, Family Member
- Annette Deleplace, Inclusion BC
- Barb Goode, UBC Centre for Inclusion and Citizenship
- Catherine Clement, Vancouver Foundation
- Cathy Anthony, Simon Fraser Society for Community Living
- Chris Reid, posAbilities
- Cinthia Page, posAbilities
- Dale Froese, UBC Centre for Inclusion and Citizenship
- Dan Collins, Langley Association for Community Living
- Doug Woollard, Community Living British Columbia
- Gord Tulloch, posAbilities
- Jeanette Moss, Vancouver Foundation
- Jessie Sutherland, Finding Home
- Joe Erpenbeck, Asset Based Community Development Cincinnati
- Julie Unger, Chilliwack Society for Community Living
- Koyali Burman, Association of Neighbourhood Houses of BC
- Laney Bryenton, Elan Consulting
- Leanne Froese, UBC Centre for Inclusion and Citizenship
- Lisa McCune, Vancouver Coastal Health
- Malerie Meeker, Vancouver Island University
- Manjeet Ghangass, Advisor
- Margot Young, UBC Faculty of Law
- Mark Sieben, Ministry of Social Development
- Meaghan Feduck, UBC Centre for Inclusion and Citizenship
- Michael Bach, Canadian Association for Community Living
- Michael McLellan, UBC Centre for Inclusion and Citizenship
- Michael Prince, University of Victoria
- Pat Feindel, Simon Fraser University
- Pilar Riano-Alcala, UBC School of Social Work
- Richard McDonald, BC People First
- Tim Stainton, UBC Centre for Inclusion and Citizenship

Did you know?

The CIC is the only university based research centre in Canada with a dedicated focus on intellectual disability policy and practice.

Any research involving human participants that is conducted at UBC facilities (including the Centre for Inclusion and Citizenship) or by persons connected to the University must be reviewed and approved by one of UBC's seven sanctioned Research Ethics Boards.

Message from the Co-Director



As I reflect on the past year, I am struck by the importance and value of the CIC team, partners, and collaborators who have invested time and energy towards strengthening the Centre and contributing to our shared successes. Without these important relationships, our vision and activities to promote inclusion and citizenship cannot be realized; so, thank you for your investment in the Centre and your involvement in our shared work.

As part of our work, we've been active in developing a programme of research in collaboration with community and government stakeholders. Last year, as part of our first annual Research With Relevance Day preceding the BC Association for Community Living Conference (now Inclusion BC), we were able to present research findings and hear from participants about the important role that research can play in informing policy and practice in BC, as well as nationally and internationally.

Continuing projects over the past year have included: research exploring stakeholders' experiences of home sharing; research on individualized funding options in BC; an evaluation of the Equipment and Assistive Technology Initiative; research examining the experiences of self-advocates transitioning from group homes to home shares in the past three years; and, a project exploring healthcare for aging adults with intellectual disabilities in BC. Our research on home sharing experiences in British Columbia is in the final stages of analysis. This research (funded by the Social Sciences and Humanities Research Council) examines the factors that contribute to positive/successful home share experiences as well as aims to identify factors that influence home sharing in negative ways.

Looking to the future, we look forward to engaging in new research projects in the areas of transitioning youth (just funded), and understanding the role of social capital in promoting inclusion. New initiatives on archiving the history of the community living movement, employment, and providing balanced information to prospective parents undergoing pre-natal testing are in development.

Our research activities aim to be of direct relevance to the community living sector and we hold close to our vision of collaborating with you in research that promotes evidence based practice that facilitates inclusion and citizenship. We look forward to sharing the research findings with you and engaging in dialogue about future projects. We invite you to continue to partner with us. Thank you to those of you who assisted us in our research activities; and, importantly, thank you to all of you who participated in the various projects.

— Dr. Rachelle Hole

Research Affiliates

- **Jennifer Baumbusch**, Assistant Professor, Nursing, UBC
- **Cam Crawford**, Director of Research, Institute for Research and Development on Inclusion and Society (IRIS)
- **Donna Drynan**, Senior Instructor & Academic Fieldwork Coordinator, Department of Occupational Science and Occupational Therapy, UBC
- **Nancy Jokinen**, Assistant Professor, School of Social Work, UNBC
- **Lyn Jongbloed**, Associate Professor, Occupational Science and Occupational Therapy, UBC
- **Sheila Marshall**, Associate Professor, School of Social Work, UBC
- **Carole Robinson**, Associate Professor, School of Nursing, UBC-O
- **Richard Young**, Professor, Educational and Counselling Psychology and Special Education, UBC

Research Assistants

Graduate Research Assistants:

- **Sevinj Asgarova**, School of Social Work, UBC
- **Genevieve Breau**, Interdisciplinary Studies, UBC
- **Sara Dieno**, School of Social Work, UBC Okanagan
- **Patricia Johnson**, School of Social Work, UBC
- **Earllene Roberts**, School of Social Work, UBC Okanagan
- **Peter Speers**, School of Social Work, UBC Okanagan
- **Jamie Tomlinson**, School of Social Work, UBC Okanagan

Undergraduate Research Assistants:

- **Carol Dean**, School of Social Work, UNBC
- **Courtenay Dennis**, School of Social Work, UBC Okanagan
- **Sarah Erickson**, Department of Occupational Science and Occupational Therapy, UBC
- **Sandy Rogers**, School of Social Work, UBC
- **Sara Wilson**, Department of Occupational Science and Occupational Therapy, UBC

“If you have knowledge, let others light their candles in it.”
— Margaret Fuller

“What we find changes who we become.”
— Peter Morville

“[Self-advocates] have the right to age with dignity as well as the rest of the British Columbians.”

— Focus group participant

“I really- when I wanted to get back in there, I needed to communicate. And unfortunately the only way that you could constantly connect... to the group of people is emails and electronic devices. I didn't have any.”

— Interview participant

Examining the Organization of Healthcare for Aging Adults with Intellectual Disabilities in British Columbia: A Critical Interpretive Policy Analysis

This study brings together researchers, Community Living organizations, and healthcare providers to examine the implementation of healthcare policy into practice. So far, over 125 people from across British Columbia have participated in focus groups and interviews. We have learned about barriers to accessing health services, such as the lack of healthcare professionals who have specialized knowledge to work well with aging adults with Intellectual Disabilities and long waitlists for specialized assessments. We have also learned about promising practices, such as the development of day programs for older adults with Intellectual Disabilities. We have met with policy-makers and presented study findings at national and international conferences.

Co-Principal Investigators: Jennifer Baumbusch, Rachele Hole

Co-Investigators: Nancy Jokinen, Tim Stainton

Research Assistants: Genevieve Breau, Carol Dean

Equipment and Assistive Technology Initiative (EATI) Evaluation Project

In partnership with the Ministry of Social Development, the BC Personal Supports Network (BCPSN) is responsible for delivering EATI. This program provides funding for assessment, training, and acquisition of assistive technology for people with disabilities who are working towards employment. This project has evaluated the broad impact of EATI on program participants with particular attention paid to the impact on employment. Since January 2012, the research team has conducted 16 interviews with program participants, 8 interviews with people who work closely with EATI, and offered a program-wide survey to learn about how EATI is experienced by people with disabilities throughout the province. The research team has recently completed the analysis and is now preparing to present the findings.

In addition to presenting at various professional conferences, the research team is also in the process of writing two articles on the findings of this study for publication. The final report and a summary of findings and recommendations will be available on the CIC in June 2013.

Principal Investigator: Lyn Jongbloed

Co-Investigators: Tim Stainton, Donna Drynan

Project Coordinator: Patricia Johnston

Research Assistants: Sandy Rogers, Sarah Erickson, Sara Wilson

Home Sharing: Exploring the Experiences of Self Advocates, Home Share Providers and Family Members

We are now writing up the findings of our research exploring Home Sharing in British Columbia. The research (funded by the Social Sciences and Humanities Research Council) aims to better understand what works well in Home Sharing and what could be improved upon to ensure a good life for people with developmental disabilities. We wanted to know about the experiences of individuals living in Home Share (self-advocates and home share providers) as well as family members. We interviewed 23 self-advocates, 31 home share providers, 12 family members, and 17 key informants from across the province. Repeatedly, people emphasized that relationships and finding “a good match” are central to achieving positive, comfortable, and safe home share living arrangements. With respect to a good match, participants explained that a “good match” includes everyone’s voice. A “good match” requires teamwork where there is clear communication about roles and expectations. These kinds of commitments foster healthy relationships and contribute to positive home share experiences. Finally, another key factor highlighted by participants was the importance of transition planning. Individuals stressed that this planning must be pro-active, not crisis-driven, and pro-active planning requires a commitment to taking the time necessary to engage all the stakeholders in planning. Final reporting of the research will be made available through the Centre’s website in the coming months.

Principal Investigator: Rachelle Hole

Co-Investigators: Tim Stainton, Carole Robinson, Cameron Crawford

Project Coordinator: Sara Lige

Research Assistants: Earllene Roberts and Peter Speers

Self Advocate Consultants: Dale Froese and Leanne Froese

Individualized Funding

The study seeks to identify and significant variations in cost and service utilization across five modalities in order to provide an accurate picture of comparable costs for similar services delivered by different means. It will also indentify any variation in service utilization across modalities to help us understand if particular service utilization patterns are associated with delivery modalities. The full research report will be available in May 2013.

Principal Investigator: Tim Stainton

Research Assistant: Sevinj Asgarova

“I would hope that home share would support the individual or be an opportunity for the individual - self-advocate, in that language, to live the life that they want to live with people who care about them and support them close by and around them. As well as an opportunity for the homeshare caregivers to gain you know the good things from that person as well... Or it's not home, and it's an institution, you know. I don't mean in the way that we think of institutions in the past I just mean... [It's just a building].”

— Home share provider participant

“Individualized Funding was developed as a way to provide individuals and families with flexible, person-centred, self-directed payment options for supports and services.”

— Tim Stainton

2012-2013 Funding

The Centre for Inclusion and Citizenship received \$164,091 in new research and project funding this year. In addition, the UBC School of Social of Social Work provided in-kind contributions valued at \$68,480, and CLBC provided \$20,000 which enabled the CIC to maintain its core operations.

Project/Research - Project Name	Funding Source	Amount	Status
An Evaluation of the Equipment and Assistive Technology Initiative	Labour Market Agreement	\$15,610	In Progress
	Social Sciences and Humanities Research Council	\$35,000 (2102 - 2013)	
Canadian Inclusive Lives Learning Initiative Pilot Evaluation and Redesign	Ministry of Social Development	\$20,000	Complete
Canadian Inclusive Lives Learning Initiative Participant Sponsorships	Community Living British Columbia	\$18,000	In Progress
	Delta Community Living Society	\$1,800	
	Family Support Institute	\$1,800	
	Inclusion BC (formerly BCACL)	\$3,600	
	posAbilities	\$3,600	
	Spectrum Society for Community Living	\$3,600	
Consultation and Discussion of Eligibility and Assessment in Disability Services	Ministry of Social Development	\$1,581	Complete
Examining the Organizational Healthcare for Aging Adults with Intellectual Disabilities in BC: A Critical Interpretive Policy Analysis	Vancouver Foundation Health and Medical Education/Research	\$39,030 (2011 - present)	In Progress
Home Sharing	Social Sciences and Humanities Research Council Standard Research Grant	\$128,320 (2009 - 2014)	In Progress
Home Sharing : Evaluating the outcomes for people who have moved from group homes to home share	Community Living British Columbia	\$25,000	In Progress
Ideas Workshop Series Speaker Sponsorship (Engaging Community)	Community Living British Columbia	\$5,000	Complete
	posAbilities	\$3,500	
UBC School of Social Work Studentships	Community Living British Columbia	\$6,000	Complete

Thank you

The activities we have undertaken this year would not have been possible without the significant contributions and the support we received from many people. We wish to thank everyone who attended the inaugural Research with Relevance Day last May in Penticton, everyone who partnered with us, presented and attended at the 2012 - 2013 Ideas Workshop Series throughout the Fall and Winter. As we prepare to finalize three research reports this Spring, we are struck by the number of self advocates, families, service providers and agencies who contributed to and informed the research by generously giving their time and sharing their experiences by completing surveys and questionnaires and participating in interviews and focus groups. We hope you will recognize your voices in the final reports.

We'd like to especially thank these organizations who made it possible for us to do our work and become a bit more steady on our feet this past year.



Thank You



“The Centre for Inclusion and Citizenship makes it possible for organizations such as Inclusion BC to advance the rights of people with developmental disabilities and promote action at a grassroots and systemic level. Accurate, leading edge research and information allows community organizations such as ours to be dramatically more effective, giving us the tools we need to promote good policies based on best practice.”

— Annette Delaplace, President, Inclusion BC

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The Centre for Inclusion and Citizenship extends this invitation to join us and take this opportunity to move forward together by building on what we know works, grounding new supports, services and systems rooted in evidence and best practice and growing BC’s reputation as an international leader in Community Living and intellectual disability.

Partnership opportunities exist at various and multiple levels from supporting research projects and conferences to establishing an endowment to create Canada’s first Research Chair in Intellectual Disability, right here at UBC.

We welcome a conversation with you.



CENTRE FOR INCLUSION AND CITIZENSHIP

Dr. Tim Stainton, Professor and Director School of Social Work, Director of the Centre for Inclusion and Citizenship, UBC
Dr. Rachelle Hole, Associate Professor and Co-Director of the Centre for Inclusion and Citizenship, UBC Okanagan
Cindy Chapman, Centre Coordinator • Meaghan Feduck, Project Coordinator, (CILLI)



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