



Research

Learning

Knowledge Exchange



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.

REPORT
SPRING 2014



a place of mind

THE UNIVERSITY OF BRITISH COLUMBIA



“The Centres’ research and community engagement activities are inspiring new ways of thinking to advance inclusion and strengthen communities.”

— Tim Stainton

Message from the Director

It has been another busy year for the Centre and it is truly exciting to see the continued growth and interest in the Centre’s work. With a significant grant from MSDSI, we were able to continue with many of our current initiatives and move forward on a number of projects. The opening of our expanded UBC-Okanagan space under the direction of Dr. Rachelle Hole was a great start to our year. The Idea’s Workshop Series, Diversity Includes, has been a great success and allowed us to build new partnerships in our community with organizations such as MOSAIC, Kwantlen Polytechnic University and a wonderful group of LGBTQ self-advocates from a Griffin Centre initiative in Ontario called sprOUT, whose contribution to our ideas workshop made this one of the most exciting events we have hosted. We also hosted a thought provoking day with AI Condeluci on Social Capital and our annual Research with Relevance day to begin Inclusion BC’s annual conference.

Our research agenda continues to grow with projects such as Homesharing continuing and many new projects including the Balanced Information and Genetic Counselling project, the Mapping Inclusive Employment project, the review of the transition in employment services to WorkBC and the transition from youth to adulthood research project. We also wrapped up our evaluation of the EATI programme, the analysis of IF cost and utilization, and a cost-benefit analysis of the Giving in Action programme. This latter is indicative of the growth of the Centre with more community driven requests for projects. Our Community Living Archive project is another good partnership which is beginning to bear fruit as the first items will shortly be going to UBC Rare Books and Special Collections.

The Canadian Inclusive Lives Learning Initiative is entering an exciting new phase as we work with school boards in the interior and community living agencies in the lower mainland to develop new delivery models which will extend the reach and improve access to the programme while reducing participant cost.

The level of student involvement with the Centre has increased as has our partnerships with other academics and community groups which is key to our mandate to enhance engagement in issues of inclusion to a broader base beyond the community living movement. I want to acknowledge the work of our Centre Coordinator, Cindy Chapman, without whom much of our work would grind to halt. I also want to thank our advisory board members who have been tremendously supportive of the Centre and whose advice has been invaluable. I particularly want to acknowledge the work of Dan Collins, our Chair, who somehow manages to fit us into his busy schedule. Finally, I must acknowledge Brian Salisbury whose vision led to the Centre’s establishment and support has been essential to our success. Brian is retiring as the CLBC representative on the board this year and will be missed.

I want to thank all of those who have supported us financially and otherwise this past year. While the funding base for the Centre remains somewhat tenuous, I am confident that next year will see us continue to grow and improve in our mission to support and foster the true inclusion and citizenship of people with intellectual disabilities and their families.

— Dr. Tim Stainton

About the Centre

The Centre for Inclusion and Citizenship (CIC) was established through an original partnership with UBC, 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 through learning, research and knowledge exchange. The CIC is the only university based research centre in Canada with a dedicated focus on intellectual policy and practice.

2013-2014 Provincial Advisory Board Members

- Angela Clancy**, Family Support Institute
Brian Salisbury, Community Living British Columbia
Dan Collins, Langley Association for Community Living
Faith Bodnar, Inclusion BC
Janice Barr, Richmond Society for Community Living
Jerry Laidlaw, Self Advocate Consultant, Mission
Kathleen Haggith, Kwantlen Polytechnic University
Laney Bryenton, Elan Consulting
Michael McLellan, Self Advocate Consultant, Comox Valley
Michael Prince, University of Victoria
Molly Harrington, Ministry of Social Development and Social Innovation
Rachelle Hole, University of British Columbia, Okanagan
Tim Stainton, University of British Columbia, Vancouver



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

Canadian Inclusive Lives Learning Initiative

The CIC's first and signature educational program continued to make waves in 2013-2014. The one-of-a-kind learning program combines face-to-face and online learning to help individuals with intellectual disabilities and their family members build an inclusive adult life. In June 2013, the second CILLI cohort of 19 participants wrapped up with a planning retreat at Camp Charis in Chilliwack. Participants in attendance presented customized plans for their future, and were presented with a certificate of completion for their achievements.



Beginning in the Spring of 2013, the CIC undertook activities to expand the CILLI reach through delivery partnerships with organizations across BC. Over the past year, engagement with three different regions has led to promising potential and lots of learning about individual, group and community needs and assets. The goal is to make CILLI course offerings available in all regions through a combination of schools, post-secondary institutions, and service providing organizations, beginning with two offerings in the Okanagan and Lower Mainland in September 2014



Graduate Student Research

Dr. Hole and Dr. Stainton have been pleased to support the following graduate students from UBC, University of Victoria and Simon Fraser University this year:

- **Assunta Rosal** (Master of Social Work, UBC Okanagan). Transitioning from group homes to home share.
- **Beth DeVolder** (Interdisciplinary Graduate Studies Program PhD, UBC). 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, UBC). Suknaquinx Knowledge and Intellectual Disability
- **Earlrene Roberts** (Interdisciplinary Graduate Studies Program PhD, UBC). University Discursive Practices and Student Subjectivity: Privileging Ability.
- **Jewelless Smith** (Interdisciplinary Graduate Studies Program PhD, UBC). Intergenerational Effects of Institutionalization in the Lives of Individuals with Disabilities
- **Pat Feindel** (PhD - Simon Fraser University). Memory and Visibility: Speaking through the Woodlands Memorial Garden.
- **Sevinj Asgarova** (PhD Social Work, UBC). Parents' Experiences of Pre-natal Testing and Intellectual Disabilities.

International Visiting Scholars & Research Students

- **Taiza Caldas**, PhD student, Federal University of Paraiba, Brazil. Researching self advocacy in Canada.
- **Ellen Walker**, PhD student, Curtin University, Western Australia. Researching microboards in Canada.
- **Michelle Browning**, PhD student, University of Melbourne, Australia. Researching supported decision making.
- **Kjersti Orvig**, Associate Professor & PhD, Sociology Department, University of Stavanger, Norway.



Studentship Awards

The 2013 - 2014 Studentships were awarded to Courtney Rogers, UBC Okanagan, Phoebe Johnston, and Margot Merinsky, 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 other organizations within the sector and contribute additional hours undertaking projects at the Centre.

Courtney, Phoebe and Margot completed their work experience placements at CLBC Kelowna, CLBC Vancouver and the BC Centre for Ability, respectively



COMMUNITY LIVING
BRITISH COLUMBIA





Message from the Chair

It continues to be my privilege to serve as the chair of the Centre's provincial advisory board. I think that you will be impressed with the body of work that has been produced this past year and see first had the value of the Centre's contribution to the community living landscape.

The Centre's success is largely a result of the combined efforts of our Director, Dr. Tim Stainton and Co-Director, Dr. Rachele Hole as well as the staff at both the Vancouver and Okanagan campuses. Without the direct and in-kind support of the University of BC, we would be hard pressed to continue. Our collaboration with UBC is invaluable, as witnessed by the growing number of faculties engaging with our research and project activities.

We are all well aware of the importance that evidenced based research provides in the development of best practice and policy. The importance and value of the contributions from a Centre such as ours can't be underestimated. Truthfully, however, I fear that it is being overlooked. We remain in a constant struggle to secure the resources required to maintain our core operations. As demand for services continue and resources remain constant, our services, practices and policies must be grounded by evidence of their value.

One of the distinguishing aspects of the Centre is in its ability to engage at a community level. This is to say that we have the opportunity to engage in research with relevance by ensuring that the voices of individuals and families as well as service providers and others interested in deepening our understanding of inclusion can influence and indeed shape the research agenda.

We are deeply grateful to those organizations that have supported the work of the Centre through direct financial support. Simply put, we require financial assistance to maintain the core operations of the Centre. I want to take this opportunity to appeal to those organizations still considering an annual contribution to the Centre to know that their gift will contribute to our ongoing viability.

The members of the advisory board contribute significantly to the Centre and continue to shape its ongoing development. As in previous years, I want to acknowledge their ongoing support. The advisory board members bring a diversity of knowledge and experience to the table and share a common belief and passion for the work.

— Dan Collins

“We are well aware of the importance that evidence based research provides in the development of best practice and policy.”

— Dan Collins



Knowledge Exchange

Professional Development & Community Engagement Events and Activities

Research with Relevance

— May 2013

In addition to providing information, sharing findings and talking with the community to receive input on current research projects, this annual event incorporated an opportunity for some of the 135 participants to experience the research process by participating in a focus group exploring the concept of social inclusion. The focus group centred on the meaning of social inclusion. After viewing a PowerPoint presentation that detailed focus group research and research ethics, participants were divided into three focus groups. Audio files were later transcribed, coded and analyzed to document and share the findings. We appreciate Inclusion BC offering us the opportunity to host Research with Relevance as the first day of their annual provincial conference.

Celebration of UBC Okanagan CIC Research Space

— September 2013

Celebrating the Centre's newly renovated and expanded research space at UBC Okanagan also provided an opportunity to deliver a presentation of "Understanding Our Past: The History of Community Living in BC" and inform community and university partners about the initiative underway to gather and preserve historical collections documenting the community living movement in BC.

Successful Change Strategies in Organization and Systems Transformation

— October 2013

Workshop, Kelowna

Presenter: Dr. Robert Schalock

Presented in Partnership with Community Living British Columbia

Social Capital – A Macro Perspective

— November 2013

Workshop and Videoconference, Vancouver

Presenter: Al Condeluci, Special Guest Lecturer, University of Pittsburgh

Presented in Partnership with the Langley Association for Community Living, Delta Community Living Society, Richmond Society for Community Living, Chilliwack Society for Community Living

Historical Collections and Archives Project

The Centre convenes and supports a Historical Collections and Archives reference group made up of self advocates, community leaders and scholars in the community living sector. The group works collaboratively to develop processes and partnerships towards the preservation of historical materials. The goal is a collection of materials that can be used by researchers, organizations, advocates and community initiatives to advance the inclusion of all citizens.

In June 2013, the reference group took the idea of a community living archive to the Inclusion BC conference, and then hosted a planning day to work out project details. The group continued to meet and work towards its vision, and in January 2014 began work with Robert McLellan, a graduate student at the School of Library and Archival Information Studies at UBC. Under the guidance of Rare Books and Special Collections archivist Sarah Romkey, Robert surveyed and appraised the first archival donation of its kind, the Jackie Maniago fonds. At the time of publication, the fonds are being processed to add to UBC's records and will be available to the public by 2015. In the coming year, the reference group will continue to work on acquiring and processing collections from Community Living organizations. Through promotions, partnerships and further collaboration, it is hoped that this legacy project will be of great value for future generations.

Reference Group Members: Barb Goode, Laney Bryenton, Lori Woods, Meaghan Feduck, Mike Keating, Pamela Cambiazo, Pat Feindel, Robert Mc Lelland, Ross Chilton, Sarah Romkey, Tim Stainton,



Professional Development & Community Engagement Events and Activities

Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding, 2015 International Conference

With the passage of the UN Convention on the Rights of Persons with Disabilities, self-determination, personalization and individualized funding initiatives have a new foundation upon which to build. In countries all over the world, these initiatives are transforming the lives of people with disabilities. Like the shift from institutions to community services, these initiatives are a momentous step forward in assisting disabled and elderly people achieve meaningful and rewarding lives as full citizens. In partnership with local, provincial, national and international organizations, and UBC's Interprofessional Continuing Education, we are pleased to be planning and hosting this international conference October 15 - 17, 2015. We invite you to join us and share in the excitement and fellowship of this important event. Mark your calendars!

Conference Committee: Catriona Johnson, Cindy Chapman, Deborah O'Connor, Faith Bodnar, Katia Selezeneva, Linda Perry, Michael Bach, Norman Kunc, Paul Gauthier, Rachele Hole, Ross Chilton, Tim Stainton

Ideas Workshop Series - "Diversity Includes"

The Ideas Workshops Series has been created by the Centre for Inclusion and Citizenship to examine issues that matter to the community living sector and all British Columbians. The series brings together self advocates, families, members of the community and subject experts, in order to collect different perspectives to discuss critical issues and identify ways to promote full inclusion and citizenship for people with intellectual disabilities.

The purpose of the series is to:

- examine topics often avoided
- expand the range of critical debate
- engage in discussion and share information
- build increased understanding
- deepen the conversation by bringing awareness

The 2014 Ideas Workshop Series, "Diversity Includes", focussed around the central theme of identifying challenges that race, culture and sexual diversity pose to the community living movement, and developing strategies aimed at improving inclusion. We'd like to thank and acknowledge the Canadian Association for Community Living (CACL), for granting us permission to use their language "Diversity Includes" for this series.

Ethnicity, Race & Culture: Towards an Inclusive Community Living Movement, January 2014

- In partnership with MOSAIC and Kwantlen Polytechnic University

Also Here, Also Queer: Building Inclusive Communities for Lesbian, Gay, Bisexual, Transgendered and Queer People Labelled with Intellectual Disabilities, March 2014

- In partnership with sprOUT, a Griffin Centre Project

Aboriginal Communities' Perspectives on Disability: Exploring the Dialogue with the Community Living Sector, May 2014

- In partnership with Okanagan Nation Alliance Wellness Committee



Presentations

Home Sharing: A study of resident and stakeholder views. Provincial Home Sharing Forum, Inclusion BC, Kelowna, British Columbia. April 2013. Presenter: Rachelle Hole

Evaluating assistive technology use: Reducing employment barriers, promoting consumer choice. The Canadian Association of Occupational Therapists (CAOT) conference, part of the Congress of Humanities and Social Sciences. Victoria, BC. May 2013. Presenters: Sara Wilson and Sarah Erickson

Equipment and Assistive Technology Initiative: A Review. Research with Relevance. Centre for Inclusion and Citizenship and Inclusion BC. Vancouver, BC. May 2013. Presenter: Patricia Johnston

Exploring participation within EATI: Implications for social work research and practice. The Canadian Association for Social Work Education (CASWE) conference, part of the Congress of Humanities and Social Sciences. Victoria, BC. June 2013. Presenter: Patricia Johnston

Examining the Organization of Healthcare for Adults Aging with Intellectual Disability. The American Association on Intellectual and Developmental Disabilities 137th Annual Conference, Pittsburgh, Pennsylvania. June 2013. Presenters: Rachelle Hole and Jennifer Baumbusch

Understanding Our Past: The History of Community Living in BC. Centre for Inclusion and Citizenship. September 2013. Kelowna, BC. Presenter: Tim Stainton

Social Capital in British Columbia: Successes, Opportunities and Pitfalls. Langley Association for Community Living, Richmond Society for Community Living, Chilliwack Society for Community Living, Delta Community Living Society. November 2013, Harrison Hot Springs, BC. Presenter: Tim Stainton

Cool Arts and the Mapping Inclusive Employment Map. Cool Arts, Kelowna, BC, January 22, 2014. Presenters: Rachelle Hole and Jon Corbett

Mapping Inclusive Employment Research Project. CLBC Community Employment Action Committee. Vancouver, B.C. February 2014. Presenters: Rachelle Hole, Jon Corbett, Shawn de Raaf

Publications and Reports

Hole, R., Robinson, C., Stainton, T., Lige, S., & Crawford, C. (in preparation). Home sharing and people with intellectual disabilities: Tips from the experts. To be submitted to American Journal on Intellectual and Developmental Disability (May 2014).

Hole, R., Stainton, T., & Wilson, L. (2013). Ageing adults with intellectual disabilities: Future hopes and concerns of self-advocates and family member experiences. *Australian Social Work*, 66 (4), 571 – 589.

Johnston, P., Currie, L. M., Drynan, D., Stainton, T. & Jongbloed, L. (2014). Getting it 'right': How collaborative relationships between people with disabilities and professionals can lead to the acquisition of needed assistive technology. *Disability and Rehabilitation: Assistive Technology*, Early Online. doi:10.3109/17483107.2014.900574.

Evans, M., Hole, R., & Stainton, T. (March 2014). Giving in Action Program Evaluation: Towards a full cost/full benefits assessment of a targeted funding program supporting in-home continuity for families with persons with special needs and/or developmental disabilities. Vancouver Foundation, 19 pages.

Stainton, T., & Hole, R. (March 2014). Submission to the Disability White Paper Consultation. Ministry of Social Development and Social Innovation, British Columbia, 12 pages.

TV, Radio and Print Media

CBC Radio West - September 19, 2013. Topic: The Centre for Inclusion and Citizenship: The opening of the CIC at UBC Okanagan and work of the CIC.

CHBC News - September 20, 2013. Topic: The Centre for Inclusion and Citizenship: the opening of the CIC at UBC Okanagan and work of the CIC.

Business Insider. November 18, 2014. Topic: Accessibility and doorknobs. "Why Vancouver's Ban On Doorknobs Makes Complete Sense".

<http://www.businessinsider.com/why-vancouvers-ban-on-doorknobs-makes-sense-2013-11>

Vancouver Sun. November 19, 2014. Topic: Accessibility and doorknobs. "Vancouver's ban on the humble doorknob likely to be a trendsetter".

<http://www.vancouversun.com/story.html?id=9173543>

Vancouver Sun. February 4, 2014. Topic: Employment. "Attitude slowly changing toward hiring people with developmental disabilities". <http://www.vancouversun.com/health/Attitude+slowly+changing+toward+hiring+people+with+developmental+disabilities/9455948/story.html>

Shaw Okanagan. February 24, 2014. Topic: Volunteerism and the Centre for Inclusion and Citizenship. <http://www.youtube.com/watch?v=4Da2u4un8m4>



Message from the Co-Director

It's hard to believe another year has passed. As I reflect on the past year, I feel privileged to have the opportunity to be a part of the important work of the CIC and to work with such a great team. One highlight for me this year was the creation of research space at the UBC Okanagan campus. We were able to celebrate the opening of the CIC at UBC Okanagan in the fall. I am thankful to the University for their investment in the Centre's work and specifically Dean Binsted and Dr. Ed Taylor for their support of the Centre at the Okanagan campus.

There are numerous research projects currently in progress as Tim has outlined. One area of research that has expanded in the last year has been a focus on employment with two projects currently under way. One of these is the mapping inclusive employment project in partnership with my colleague, Dr. Jon Corbett, and the BC Centre for Employment Excellence. This community-based project involves the development of an online mapping tool that will allow individuals to share and to learn about inclusive employment experiences in British Columbia. In particular, in this project we aim to identify factors that facilitate and contribute to positive, inclusive employment experiences for individuals with intellectual disabilities in B.C. as well as to learn how service providers, employers and other key individuals are able to support individuals in their employment journey. The online tool is currently being developed with input from selfadvocates and an advisory group. We will be working with stakeholders across the province to populate the tool and to learn more about inclusive employment experiences in our province.

Finally, in the past, I have spoken of the importance our community connections have with respect to our research and community engagement activities. This continues to be true. Thank you to all of those who have participated with us in the work of the CIC. Your partnerships, support and collaborations are invaluable.

— Dr. Rachelle Hole

“The work we are doing with our community and academic partners reinforces my belief in the power of knowledge to impact social change.”

— Rachelle Hole



Research Affiliates

- Jehannine Austin, Associate Professor, Department of Psychiatry and Medical Genetics, UBC
- Michael Bach, Executive Vice-President, Canadian Association for Community Living
- Jennifer Baumbusch, Assistant Professor, School of Nursing, UBC
- Stephanie Bryson, Assistant Professor, School of Social Work, UBC
- Jon Corbett, Associate Professor, Community, Culture and Global Studies; Centre for Social, Spatial and Economic Justice, UBC-O
- Cam Crawford, Director of Research, Institute for Research and Development on Inclusion & Society
- Shawn De Raaf, Research Coordinator, BC Centre for Employment Excellence
- Donna Drynan, Senior Instructor & Academic Fieldwork Coordinator, Department of Occupational Science & Occupational Therapy, UBC
- Mike Evans, Professor, Community, Culture and Global Studies; Centre for Social, Spatial and Economic Justice, UBC-O
- Catriona Hippman, President, Canadian Association of Genetic Counsellors
- Nancy Jokinen, Assistant Professor, School of Social Work, UNBC
- Lyn Jongbloed, Associate Professor, Occupational Science & Occupational Therapy, UBC
- Sheila Marshall, Associate Professor, School of Social Work, UBC
- Filomenda Parada, Post-doctoral Fellow, Coimbra University, Portugal
- Sarah Romkey, Archivist, Rare Books & Special Collections, UBC Library
- Carole Robinson, Associate Professor, School of Nursing, UBC-O
- Leyton Schnellert, Assistant Professor, Faculty of Education, UBC Okanagan
- Jenna Scott, Program Coordinator, Genetic Counselling Program, Department of Medical Genetics, UBC
- Richard Young, Professor, Educational and Counselling Psychology & Special Education, UBC
- Anat Zaidman-Zait, Associate Professor, Education, Tel Aviv University, Israel

Research Assistants

Graduate Research Assistants

- Sevenj Asgarova, School of Social Work, UBC
- Jon Breen, School of Social Work, UBC
- Deirdre Curle, Education & Counselling Psychology and Special Education, UBC
- Beth DeVolder, Interdisciplinary Graduate Studies, UBC Okanagan
- Sophie Hzuma, Education & Counselling Psychology and Special Education, UBC
- Patricia Johnston, School of Social Work, UBC
- Robert McLelland, School of Library and Archival Information Studies, UBC
- David Munro, Education & Counselling Psychology and Special Education, UBC
- Sarah Predham, Genetic Counselling Program, Department of Medical Genetics, UBC
- Earlene Roberts, Interdisciplinary Graduate Studies, UBC Okanagan
- Assunta Rosal, School of Social Work, UBC Okanagan
- Jewelles Smith, Interdisciplinary Graduate Studies, UBC Okanagan
- Merel Voth, School of Social Work, UBC Okanagan
- Jessie Wall, Education & Counselling Psychology and Special Education, UBC

Undergraduate Research Assistants

- Sara Dieno, School of Social Work, UBC Okanagan
- Phoebe Johnston, School of Social Work, UBC
- Margot Merinsky, School of Social Work, UBC
- Courtney Rogers, School of Social Work, UBC Okanagan

"Through the CIC I have had the opportunity to meet self advocates with intersecting barriers, hear stories of institutional abuse from survivors, be included in thought-provoking debates about ethical dilemmas in the field and learn about complex and often multi-mandated service systems people with intellectual disabilities must work with. Working with the CIC has been an incredibly rewarding introduction to the community living sector."

Phoebe Johnston,
BSW Student
and Research Assistant

Spotlight on Research

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

This three year research project is in its final stage. The research aimed to better understand what works well in home sharing and what could be improved upon to ensure a good life for people with intellectual disabilities. We wanted to know about the experiences of individuals living in home share and well as their family members.

Home sharing is a residential living arrangement in which one or more adults with intellectual disability shares a home with an individual or family (non-custodial) who is contracted to provide support. Home sharing is the fastest growing residential option in British Columbia increasing 350% over the past 15 years with over 50% of individuals receiving residential support living in home sharing. A paucity of research exists regarding home sharing practices including the experiences of stakeholders affected by home sharing, particularly the individuals with intellectual disability. Using interpretive description, a qualitative method, we explored the home share experiences of adults with intellectual disability, home share providers, family members, and key informants in BC (N = 85). Specifically, we identified factors that contribute to positive home sharing experiences as well as those that constrain and undermine home sharing goals of promoting independence.

Participants overwhelmingly underscored the importance of finding a "good match" where there was a connection and positive relationship between the home sharing members (individual and home share provider). Some further emphasized that family members were an important part of making up the "good match" (both family members of the individual with intellectual disability as well as the home share provider's family). Pro-active planning was identified as an essential practice to find the "good match"; e.g., individuals entering into a home share relationship should have opportunities to get to know one another (e.g., overnight visits) or have a pre-existing relationship. Other dimensions of pro-active planning included support for providers and individuals with intellectual disability during the transition phase as well as an openness to share necessary information about the individual in order to ensure that proper supports are in place. With respect to ongoing success, findings highlight the importance of ongoing communication and teamwork. Participants' narratives underscored the complex interactions of stakeholders and systems impacting the home share relationship(s). Communication and teamwork that included everyone was emphasized repeatedly. Finally, participants shared that although transition planning was central to finding a "good match" and successful home sharing experiences, "ongoing planning" was essential as all participants' needs and situations change over time. This became particularly apparent when participants spoke about issues related to aging - both aging for home share providers but also aging individuals with intellectual disability.

These findings contribute to our understanding of how to better support individuals with intellectual disability living in home share as well as the other stakeholders involved in this residential option including service providers and policy makers. Finally, understanding how to meet the residential needs and desires of individuals with intellectual disabilities is in line with Canada's commitment to the UN Convention on the Rights of Person with Disabilities (2006) Article 19a that states: persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

Investigators: Rachelle Hole (PI), Tim Stainton, Carole Robinson, Cameron Crawford

Research Team: Sara Lige, Earlene Roberts, Peter Speers, Dale Froese, Leanne Froese



Research Projects

Balanced Information and Genetic Counselling

Genetic counselling has emerged as a key profession with the advent of widespread genetic testing and is the key vehicle through which information is transmitted to prospective parents when a disability related trait is identified. This proposed 4 year study, in partnership with the Canadian Association for Community Living, the Canadian Association of Genetic Counsellors and others, seeks to address gaps in our knowledge, curriculum and information through a two pronged multi-phased study which develops, tests and evaluates both the content and delivery of: 1) disability related information provided to prospective parents and 2) disability curriculum for use in genetic counselling and other relevant health care education programmes.

Investigators: Tim Stainton, Catriona Hippman, Jehannine Austin, Jenna Scott, Rachele Hole
Research Team: Michael Bach, Sarah Predham

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

The study brings together researchers, community living organizations, and healthcare providers to examine the implementation of healthcare policy into practice. In BC, Health Services for Community Living (HSCL) is a provincial policy, introduced following the closure of institutions for adults with ID, which specifically addresses the healthcare needs of this population. The aim of this study is to increase understanding of potential policy-practice gaps in the implementation of HSCL and other relevant policies. Data has been collected through policy analysis, focus groups, and key informant interviews with over 125 people from throughout the province. Data analysis is currently underway and findings will generate new knowledge about healthcare for aging adults with ID and will lead to recommendations for policy and service renewal in this area.

Investigators: Jennifer Baumbusch, Rachele Hole, Nancy Jokinen, Tim Stainton

"Research is critical to advancing the rights of people with intellectual disabilities, ensuring that policy and practise align in a way that promotes full inclusion and citizenship. The work of the CIC is essential as we gain a deeper understanding of how human rights frameworks impact inclusion, provincially, nationally and internationally, and also how they interface with and shape practise in the day-to-day lives of people with intellectual disabilities. Inclusion BC is fully committed to the CIC, knowing that research provides the foundation that guides and challenges all of us to move forward in ensuring people with intellectual disabilities are supported to assume full citizenship."

Faith Bodnar,
Executive Director,
Inclusion BC



Research Projects

Equipment and Assistive Technology Initiative (EATI) Evaluation Project

The evaluation of the Equipment and Assistive Technology Initiative (EATI) was completed in the fall of 2013. EATI offers funding for assessment, training, and acquisition of assistive technology (AT) for people with disabilities who are working towards employment in British Columbia. The Evaluation explored both the impact of the AT and the impact of the program's underlying philosophy (the Participation Model) on the lives of people with disabilities who received AT through the program. It also examined the decision-making that occurs between the government and the community to administer the program. The Evaluation included a survey with those who have engaged with EATI and a series of interviews with program participants who received AT. The evaluation was conducted with the support and involvement of the EATI Evaluation Committee, made up of stakeholders from within the British Columbia Personal Supports Network (BCPSN) and the Government of British Columbia's Ministry of Social Development (MSD), administrators and staff working with EATI, and health professionals within the community.

Investigators: Lyn Jongbloed, Tim Stainton, Donna Drynan

Research Team: Patricia Johnston

Giving in Action Program Evaluation

The Giving in Action Project was a cost benefit analysis of the Giving in Action Fund (GIA) administered by the Vancouver Foundation. The GIA has two components - the Family Independence Fund (FIF) and the Children and Youth with Special Needs (CYSN) - both with a core intent to support individuals and their families in the home environment. Grants administered through this program go towards the costs associated with home renovations and retrofits, and purchasing vehicles configured to accommodate the disabilities require; both types of expenditures are for the purposes of ensuring that the family member can remain at home, living with their families in their communities, and in supportive surroundings both comfortable and appropriate. Dr. Mike Evans from UBC Okanagan took the lead on this project which was completed March 2014.

Investigators: Mike Evans, Rachele Hole, Tim Stainton

Home Sharing: Evaluating the Outcomes for People who Have Moved from Group Homes to Home Share

This mixed-methods research project, initiated and funded by Community Living British Columbia, will evaluate the outcomes for people who have moved from group home living arrangements into home sharing arrangements since 2007. An emphasis will be given to understanding individuals' satisfaction in their current home sharing experience with special focus on understanding their current quality of life (QoL) as informed by Dr. Schalock's QoL index. The design will consider multiple perspectives (e.g., self-advocates, home share providers, and family/friend/caregiver perspectives) and will incorporate both quantitative and qualitative methods.

Investigators: Rachele Hole, Tim Stainton

Research Team: Sevinj Asgarova, Assunta Rosal

"At FSI, we believe that families are the best resource available to support one another. The work being done by the Centre promotes and supports family leadership, sustainable models of support that positively impact families throughout BC, and assists in research to support family circumstances and need. The Centre's work has also enabled people to come together to have difficult yet extremely valuable conversations and learning experiences with courage, expertise and grace. The Centre's leadership in the past year's main areas of focus have allowed for people to become more engaged, informed and empowered."

Angela Clancy,
Executive Director,
Family Support Institute

Research Projects

Mapping Inclusive Employment Practices for Individuals with Developmental Disabilities: A Participatory Research Mapping Approach

This project is developing, implementing and testing an online interactive database, The BC Employment Mapping Tool, that will function as an accessible, searchable online mapping database of best practices concerning the employment of people with developmental disabilities. The tool is being designed to serve as a resource for service providers (employment and community living providers), employers, individuals with developmental disabilities and their families, as well as policy makers to learn and to share examples of innovation in the area of employment, including examples of how to best support individuals in preparing for employment and/or examples of how employers can address barriers to support for individuals with disabilities. The project team is currently consulting with self advocates to develop the website, and pilot the site in groups to gain input on the website's accessibility and usability. The online tool will 'go live' in 2015, for others to publicly add their employment experiences.

Investigators: Rachelle Hole, Jon Corbett, Tim Stainton, Shawn de Raaf

Research Team: Sara Lige

Service Restructuring, Employment Outcomes and Opportunities for People with Disabilities in BC's Labour Market

This study proposes to document and explore the intersection between employment service restructuring and employment outcomes for people with disabilities in British Columbia, with a particular focus on the impact of the decline in small community based employment service providers. Our goal is to learn about how changes in employment service provision have impacted people with disabilities in British Columbia over the past decade. A literature review and narrative is currently being finalized and focus groups and interviews with employment service providers and service recipients have been conducted. Data analysis will occur in the summer of 2014.

Investigators: Rachelle Hole, Tim Stainton

Research Team: Jon Breen, Beth DeVolder, Sara Lige, Jewelles Smith, Phoebe Johnston



Research Projects

Individualized Funding

This study sought to identify any 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 also identifies variations in service utilization across modalities to help us understand if particular service utilization patterns are associated with delivery modalities. This study supports the view that IF methods can cover almost all services supported by CLBC at a cost mostly equal to, or lower than, traditional block funded services. From a cost perspective, both direct payments and host agency modes of Individualized Funding would seem to offer the most economical options; however, microboards may offer equal or better value for money when other things are considered (e.g., building relationships and community connections, ongoing network support and ability to support persons with complicated support needs). This study was completed in May 2013.

Investigators: Tim Stainton

Research Team: Sevinj Asgarova

Transition to Adulthood as Goal-directed Projects for Youth with Intellectual Disabilities and Their Parents

The purpose of this three year research project is to identify and describe the naturally occurring processes between parents of young adults with intellectual disability as they navigate the transition to adulthood. This study focuses on describing how parents co-construct the transition to adulthood for their son or daughter with intellectual disability. The qualitative action project method is being used to collect and analyze data. The analysis of data focuses on goal-directed actions over time, during the transition to adulthood. Findings will be reported as identified projects, detailing meaning (goals), actions steps, cognitive and emotional steering and regulation, and behavior and resources used. This study will shed light on the particular challenges that parents in this group face relative to the transition to adulthood, and how they jointly go about addressing them. Practitioners will be able to base interventions and support on information about parents' specific goals and strategies.

Investigators: Richard Young, Sheila Marshall, Tim Stainton

Research Team: Deirdre Curle, Sophie Hzuma, David Munro, Filomenda Parada, Jessie Wall, Anat Zaidman-Zait

Research is important because it:

- helps us better understand issues and systems
- provides evidence that can be used to inform policy and practice
- advances community inclusion
- strengthens communities



Research Projects

Sexual Health Knowledge

The question guiding the research is, "What are the experiences of sexual education and knowledge acquisition among adults with an intellectual disability?" Sexual knowledge is when someone learns about sexual relationships, gets information about their body, and receives information about safety and health issues to do with sex. There has been very little research done about this topic. The goals of the research are to: 1) find out where and how adults with intellectual disabilities receive formal and informal sexual education and knowledge, and 2) determine what adults with intellectual disabilities feel would be important information to have in regards to sexual knowledge. Understanding how adults with intellectual disabilities come to know sexual health information will help to inform policy and programs for individuals with intellectual disabilities. Interviews with self advocates are now being conducted and the project is expected to be completed in the Fall of 2014.

Investigator: **Rachelle Hole**

Research Team: Sara Lige, Courtney Rogers, Phoebe Johnston, Sara Dieno, Merel Voth

"Research can sometimes seem complicated and it needs to be explained in ways that everyone can understand. We're making plain language fact sheets to help people learn more about what research is, why it is important, and explain how self advocates and others can get involved. We're thinking outside the box".

Barb Goode,
Plain Language Consultant

Research Consultations

As awareness of the Centre continues to grow, we have been pleased to be able to respond to these requests from community to discuss their research needs. While not every idea or discussion leads to a project, we'd like to thank members of the community for approaching us to discuss potential opportunities and partnerships.

- **Mark Flynn & Debbie Holmes**, Foundations Program, Surrey School District. Proposed Criminal Justice Advocate for People with Developmental Disabilities
- **Jai Birdie & Linda Moyneur**, Provincial Assessment Centre, Community Living British Columbia



2013-2014 Funding

The Centre generated \$368,693 in new research and project funding this year. UBC's in-kind contributions were in excess of \$156,380 and the Ministry of Social Development and Social Innovation provided a \$175,000 grant to maintain and expand community engagement, learning and knowledge exchange activities and to support our core operations.

| Project/Research - Project Name | Funding Source | Amount | Status |
|---|--|----------------------------|-------------|
| An Evaluation of the Equipment and Assistive Technology Initiative | Labour Market Agreement | \$15,610 | Complete |
| | Social Sciences and Humanities Research Council | \$35,000 (2012 - 2013) | |
| Balanced Information and Genetic Counselling Project | Centre for Inclusion and Citizenship | Not Funded | In Progress |
| Examining the Organizational Healthcare for Aging Adults with Intellectual Disabilities in BC: A Critical Interpretive Analysis | Vancouver Foundation Health and Medical Education/Research | \$39,030 (2011- 2014) | In Progress |
| Giving in Action | Vancouver Foundation | \$5,000 | Complete |
| Home Sharing: Evaluating the Outcomes for People who Have Moved From Group Homes to Home Share | Community Living British Columbia | \$20,000 (2013 - 2014) | In Progress |
| Home Sharing: Exploring the Experiences of Self Advocates, Home Share Providers and Family Members | Social Sciences and Humanities Research Council Standard Research Grant | \$128,320 (2009 - 2014) | In Progress |
| Mapping Inclusive Employment Practices for People with Developmental Disabilities | The Social Research and Demonstration Corporation from the Ministry of Social Development and Social Innovation with the BC Centre for Employment Excellence | \$99,500 (2013 - 2015) | In Progress |
| Service Restructuring, Employment Outcomes and Opportunities for People with Disabilities in BC's Labour Market | IAM Cares Society | \$88,943 | In Progress |
| Sexual Health Knowledge | Centre for Inclusion and Citizenship | Not Funded | In Progress |
| Transition to Adulthood as Goal-directed Projects for Youth with Intellectual Disabilities and Their Parents | Social Sciences and Humanities Research Council of Canada | \$172,950 (2013 - 2016) | In Progress |
| Historical Archives and Collections | Community Ventures Society | \$300 | In Progress |
| Ideas Workshop Series | Office of the BC Representative for Children and Youth | \$2000 | Complete |

What people say about the Centre

Brian Salisbury, CIC Advisory Board Member, Community Living British Columbia

The Centre for Inclusion and Citizenship is a one of a kind body in Canada that plays a key role in furthering the inclusion and full citizenship of people with intellectual disabilities and their families.

The Centre has made many significant contributions to public policy and practice, for example, the Centre recently made a submission to the provincial government's Disability White Paper using evidence drawn from the numerous studies it has undertaken in recent years. The White Paper will help shape BC's disability support system for decades to come. One of the Centre's successful initiatives has been the Canadian Inclusive Lives Learning Initiative, a unique learning program for individuals with developmental disabilities and their families.

The Centre also makes a wide range of resources available on its website and conducts public workshops to support sector wide learning. Of special interest is a new site on the history of intellectual disability. One current research project is capturing, studying and sharing best practices on employment of people with developmental disabilities in BC using an interactive online mapping database. This is important inasmuch as we all know that employment is the key gateway to a life as a full citizen.

It is an honor to serve on the Centre's diverse Advisory Board to help develop a deeper understanding of the different ways to advance the inclusion and full citizenship of individuals with developmental disabilities in British Columbia and beyond.

Ideas Series Workshop Participants...

"Best day in a long, long time - thank you! I've worked in the field for over 30 year and have never had this conversation."

"Great to network and include others so we are not preaching to the same choir. It makes me think about all the partnership opportunities we have missed."

"I'll go back to work and continue this conversation there. I hadn't thought about intersectionality this way before."

Thank You

We would like to thank everyone who made the time to contribute to our collective work by completing a survey, being interviewed or attending a focus group; for partnering with us to create and deliver workshops and for participating in important dialogues.

We'd like to acknowledge the in-kind and financial support received from the Ministry of Social Development and Social Innovation and the University of British Columbia in 2013 - 2014.





Learning



Research



Knowledge Exchange

Contact Us

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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 and Sara Lige, Project Coordinators



a place of mind

THE UNIVERSITY OF BRITISH COLUMBIA