REPORT • SPRING 2012

Centre for Inclusion and Citizenship

The Centre for Inclusion and Citizenship is a partnership between 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.



a place of mind

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







Welcome

With a focus on learning, research and knowledge exchange in the field of intellectual disability, the Centre for Inclusion and Citizenship is working to inspire and inform social change by creating a passion and culture for inclusion.

It is a pleasure for us to have this opportunity to share this report and invite you to join us in our work.

The dedication, support and commitment received from the members of our volunteer provincial advisory board, community and government partners has enabled us to establish our roots through a variety of projects and initiatives.

While we are still relatively new, we feel we address an important gap in the movement for full inclusion of people with intellectual disabilities and we hope you will find our work both informative and inspiring.

Please visit our website at www.cic.arts.ubc.ca to review the full research reports, literature reviews and project updates.

We're looking forward to creating more opportunities to engage with the community, share what we've been learning and hear your ideas about how we can work together to achieve our mutual goals. Please be in touch. We'd welcome your feedback and involvement.

Dr. Tim Stainton, UBC Vancouver, Director

Dr. Rachelle Hole, UBC Okanagan, Co-Director

Dan Collins, Advisory Board Chair

Mission

The Centre for Inclusion and Citizenship envisions a society that acts to achieve lives of quality for all citizens. We inspire and inform social change by creating a passion and culture for inclusion. We work with the community, government, and the private sector to secure justice, equality, and well-being of all citizens.

Who we are

The Centre for Inclusion and Citizenship is part of the School of Social Work at the University of British Columbia. Dr. Tim Stainton, (UBC Vancouver) is the Director and Dr. Rachelle Hole, (UBC Okanagan) is the Co-Director.

The Centre is supported by an advisory board of community members representing self-advocates, families, service providers and academics who advise on priorities and directions and participate on project specific working groups. Currently, the Center has one part-time coordinator and one graduate student assistant.

We are pleased to have the support and involvement of our research affiliates and graduate students undertaking studies related to intellectual disabilities in a variety of areas.

The Centre is presently exploring opportunities to expand our partnerships with community, academic and government organizations.



Provincial Advisory Board Members

Dan Collins, Chair Faith Bodnar Angela Clancy Gordon Fletcher

Research Affiliates

Jennifer Baumbusch

Kathleen Haggith Molly Harrington Jessica Humphrey (past) Angie Kwok

Lyn Jongbloed

Jerry Laidlaw Michael Prince Brian Salisbury







earning

Canadian Inclusive Lives Learning Initiative

The Canadian Inclusive Lives Learning Initiative (CILLI) is a one-of a kind pilot project designed by the Centre for Inclusion and Citizenship to offer tools and information to help individuals with intellectual disabilities and their family members to build an inclusive adult life. The course combines two in-person retreats, eight online modules, two "live" sessions each month, and an interactive planning tool.

In 2009, the Centre received a development grant from Community Living BC to help create a course for people with intellectual disabilities and their families. Through many consultations with experts and community groups, the Centre identified the critical areas for building an inclusive life and structured the curriculum around these.

The eight modules of learning include:

- Putting your plan into action
- Supported Decision Making
- Community Connections
- Employment
- Financial Literacy
- Lifelong Learning
- Creating a Home
- Transitions

Newport Bay Consulting was recruited to write the online modules, and a grant was received from the Government of Canada to make the course accessible to people with disabilities.

The first CILLI course was launched as a "pilot" in September 2011 with a group of 21 participants from British Columbia. The purpose of the pilot is to test the course, get feedback from the participants, and find out how to improve or change the course to make it the most effective. This first group of participants will finish the course in June 2012.

The Centre is currently seeking funding and partners to enable us to continue to offer CILLI.

Post Qualifying Certificate Program (PQCP)

The Centre for Inclusion and Citizenship is exploring opportunities to develop a coherent, widely available, and flexible program of learning for professionals working within the community living sector in BC. The program will address the following concerns identified by the sector:

- Health and social care professionals are typically under prepared for practice in supporting persons with intellectual disabilities.
- Social workers and related professionals, in particular, are often insufficiently prepared theoretically and practically to provide innovative and effective services and supports in this domain.
- British Columbia lacks a coherent strategy for best and promising practices in professional development and learning opportunities in relation to supporting persons with intellectual disabilities, traditionally relying on experience and ad hoc training events.
- Much of the training that occurs is geographically located in the lower mainland limiting further opportunities for those in other areas of the province, particularly the North and remote areas.

Graduate Student Research

The Centre for Inclusion and Citizenship is becoming an environment rich in knowledge gained through research undertaken by graduate students. Dr. Hole and Dr. Stainton have been pleased to support the following students:

- Peter Speers (IGS PhD student, UBC O) Physical Fitness and Intellectual Disability
- Earllene Roberts (IGS PhD student, UBC 0) Disabled Graduate Students' Experiences of University
- Donna Good Water (IGS PhD student, UBC 0) Intersections of Disability and Aboriginal Issues
- Sara Lige (MA student complete UBC 0) Self-Advocates' Experiences of Art-Making
- Sarah Dieno (MSW student UBC 0) Self-Advocates' Experiences of Sexual Education
- Meaghan Feduck (MSW student UBC V) Remembering the Woodlands' Centre Block Demolition: Using PAR
- Jamie Tomlinson (MSW student UBC O- complete) Supported Employment and Adults with Intellectual Disability
- Jill Mitchell (Interdisciplinary MA, UBC 0) Disability and Discourses of Genocide
- Sevinj Askerova (doctoral student at UBC V)
- Sarah Baumbusch (MSW student UBC V- complete) Life in the Later Years: An Exploration of the Meaning of Retirement to Ageing Self Advocates
- Arby Yeo (MSW Student UBC V) Negotiating the Hearing-Deaf Sibling Relationship Across the Lifespan

Studentship Awards

With the ongoing support from Community Living British Columbia, the Centre has been able to offer studentships for BSW and MSW level students at UBC interested in working in the field of intellectual disabilities. The awards encourage students to consider a career in the area of community living upon completion of their degrees 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. The students complete their work experience placements at CLBC and contribute additional hours working with the Centre. Every student who received this award in 2009-2011 has accepted employment in the field.

Studentship Award Recipients:

2011-2012

Sarah Dieno Karlena Siwy Meaghan Feduck

2010-2011

Yousra Seyda Taru Tamminen Jamilla Kamrudin Cherise Neilson

2009-2010

Rosiland Moret Susan Wells Vanessa Jonson Sara Bergen





New resources now available at www.cic.arts.ubc.ca

Colloquia Series on Inclusion

The Centre has been pleased to welcome and host visiting scholars, community members and professionals to present as part of our ongoing Colloquia Series on Inclusion. This series of free events is open to people with intellectual disabilities and their families, students, academics, professionals, and community members. The following presentations have been hosted:



PRIDE & PREJUDICE: Canadian Ambivalence Toward Inclusion - Dr. Michael J. Prince



SWINGS & ROUNDABOUTS: The Social Inclusion Agenda in Australia and it's Impacts - Dr. Lesley Chenoweth



QUALITY OF LIFE & INTELLECTUAL DISABILITY: Concepts & Measurment - Dr. Bob Schalock



THE AGE OF EMPATHY, THE EXILE OF AUTISM - Dr. Patrick McDonough



HELPING PEOPLE WITH INTELLECTUAL DISABIL-ITY HAVE THEIR OWN ASPIRATIONAL VOICE: From "Non-Verbal" to "Uniquely Verbal" - Dr. Leighton Jay and Linda Perry



LIVING WITH AUTISM:

Adults with Autism Spectrum Disorders Speak Out! - Autism Society Canada



MOVING BEYOND IQ IN DEFINING AND DIAG-NOSING INTELLECTUAL DISABILITY: Service Eligibility Inequities for People with Brain-Based Disorders

- Dr. Stephen Greenspan

Professional Development Opportunities

The Centre is committed to creating and participating in ongoing opportunities to further the development of students, members of the community and professionals working in the community living sector.

Mentoring at Work.

The CIC was pleased to host Dr. Jane Fowler, a Senior Lecturer in the School of Human Services and Social Work at Griffith University in Queensland, Australia, an Adjunct Professor at West Virginia University.

Dr. Fowler has delivered this interactive workshop exploring mentoring processes and practices from the perspectives of mentees, mentors, and organizations as a whole. Topics included the functions and benefits of mentoring, methods of creating and developing mentoring relationships for individuals including goal-setting and monitoring processes, and how to implement organization-wide mentoring programs.

Community Presence & Engagement

As awareness of the Centre and our work increases, so do the opportunities we have to share the learnings and further disseminate research findings. Dr. Stainton and Dr. Hole have been invited to and have presented at numerous provincial, national and international conferences and have hosted visiting scholars from around the world.

Resources

Literature Reviews

- Individualized Funding
- Supported Employment for Adults with Intellectual Disabilities: Social and Economic Outcomes

Reading List

Organizational Participation

Discussion Papers

- Paving the way to Full Realization of the CRPD's Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective (Lana Kerzner, 2011)
- Supported Decision Making: legal fiction or grounded practice (Michael Bach, 2011)
- Rethinking Personhood: New Directions in Legal Capacity Law & Policy OR How to put the "Shift" back into "Paradigm Shift" (Gerard Quinn, 2011)
- Moral Status: What a Bad Idea! Why discard it? What replaces it? (Anita Silvers, 2011)

"I don't know if these words adequately express this deeper awareness I have but please know how grateful I am for it, and I look forward to putting into practice what I am taking away from that day."

> Mentoring at Work, workshop participant

Did you know?

- Between 0.5% and 3% of adults have Intellectual Disabilities.
- Research conducted by the CIC has been published in the Journal of Intellectual Disability?



Artwork by: Ben Volk

Supported Decision Making

In May of 2011, the Centre coordinated an international symposium funded by the Peter Wall Institute for Advanced Studies. This initiative brought together leading national and international scholars from Law, Disability Studies, Gerontology, Social Work, Ethics, Medicine, Psychology and Philosophy along with key civil society representatives to examine from a 'ground up' perspective the issues raised by Article 12 of the United Nations Convention on the Rights of Disabled Persons. The initiative focused on: 1) the conceptual foundations of moral and legal personhood; 2) the definition and criteria for legal capacity found in ethics and law; 3) implications for law and policy for adult protection, substitute and supported decision-making, health and social care consent, contract and criminal law; and 4) emerging social and legal forms of support and reasonable accommodation that enable people with significant cognitive or psychosocial disabilities to maximize their legal capacity.

Over 40 people from 11 countries (Argentina, Australia, Canada, Croatia, Germany, Hungary, India, Israel, Sweden, United Kingdom and United States) contributed to and participated in the event that resulted in 3 discussion papers being prepared, presented and discussed.

In the past three years, under the banner of the Community Living Research Project funded by Community Living British Columbia, the Centre has completed and published research reports in the following areas:

Adult Community Living Supports Non-Residential Supports in BC Residential Alternatives Services for Seniors with Developmental Disabilities Survey of Family Members Young Adults Transitioning from High School Home Sharing : A Review of Current Practice and Policy Recommendation, 2008

As part of our commitment to knowledge exchange and sharing information is accessible formats, many of these reports have also been summarized in plain language. These reports are available at www.cic.arts.ubc.ca

Did you know?

- Individualized Funding (IF) provides individuals and families with flexible, person-centered, self-directed payment options for arranging, managing, and paying for supports and services.
- Home Sharing is the fastest growing residential option in BC.

Research

Current Research Projects

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

This research explores the experiences of individuals living in Home Sharing living arrangements (self-advocates and home share providers) and family members of adults with developmental disabilities living Home Shares. Our goal is 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.

Principal Investigator: Rachelle Hole

Co-Investigators: Professor Tim Stainton, Dr. Carole Robinson, Cameron Crawford Project Coordinator: Sara Lige

- Research Assistants: Earliene Roberts and Peter Speers
- Self-Advocate Consultants: Dale and Leanne Froese

Individualized Funding

The study seeks to identify any significant variations in cost and service utilization across five service modalities in order to provide an accurate picture of comparable costs for similar services delivered by different means. It will also identify any variation in service utilization across modalities to help us understand if particular service utilization patterns are associated with delivery modalities. Principal Investigator: Tim Stainton Research Assistant: Sevinj Askerova

An Evaluation of the Equipment and Assistive Technology Initiative

In partnership with the Ministry of Housing and Social Development, the BC Personal Supports Network is responsible for delivering the EATI which provides a source of funding for assessment, trialing, acquisition and/or training with equipment and assistive devices for people with disabilities who have employment or voluntarism goals. This project will seek to evaluate the broad impact of the program on users in terms of employment, employment readiness and other impacts. Co-Principal Investigators: Lyn Jongbloed, Tim Stainton Co-Investigator: Donna Drynan

Research Assistants: Patricia Johnson

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. The aim of this study is to increase understanding of potential policy-practice gaps in the implementation of HSCL and other relevant policies. Findings from this research will generate new knowledge about healthcare for aging adults with ID and will lead to recommendations for policy and service renewal in this area.

Co-Principal Investigators: Jennifer Baumbusch, Rachelle Hole Co-Investigators: Nancy Jokinnen, Tim Stainton Research Assistants: Jamie Tomlinson, Peter Speers "Our goal is 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."

Research and Project Funding

The Centre for Inclusion and Citizenship was established in 2009 with an initial start up grant of \$100,000 from Community Living British Columbia, and in 2011 received \$20,000 from the UBC Dean of Arts to support our infrastructure costs.

To date, the Centre has secured more than \$661,000 in research and project funding through a variety of sources.

Project/Research - Project Name	Funding Source	Amount	Status
Community Living Research Project	Community Living British Columbia	\$325,000	Complete
Canadian Inclusive Lives Learning Ini- tiative (CILLI) content development	Community Living British Columbia	\$50,000	Complete
CILLI accommodation supports	Human Resources Development Canada	\$12,165	Complete
UBC School of Social Work Student- ships	Community Living British Columbia	\$18,000	Ongoing
Home Sharing	SSHRC Standard Research Grant	\$128,320	In Progress
Supported Decision Making	Peter Wall Institute for Advanced Studies, UBC,	\$20,000	Complete
International Dialogue on Supported Decision Making	Open Society Institute Foundation	\$26,000	Complete
Examining the Organization of Health- care for Aging Adults with Intellectual Disabilities in BC: A Critical Interpre- tive Policy Analysis	Vancouver Foundation – Health and Medical Education/Research	\$39,030	In Progress
Supported Employment for Adults with Intellectual Disabilities: Social and Eco- nomic Outcome, A Literature Review	Community Living British Columbia	\$3000	Complete
Transitioning to Adulthood: Challenges Facing BC's Youth	PPBC Environmental and Occupational Health Research Network BCEOHRN 2008 Research Capacity Development Grant	\$10,000	Complete

Research affiliates

Jennifer Baumbusch



Lyn Jongbloed



Thank You

We' d like to extend our sincere thanks to everyone who has supported our work through our development. There are too many individuals to name but we thank the self advocates, families, professionals and community members who have participated in focus groups, reviewed and edited our materials, and offered their guidance. In addition to the project and research funding, other financial support from these organization has made our work possible.

Community Living British Columbia British Columbia Association for Community Living Newport Bay Consulting Spectrum Society for Community Living PosAbilities Langley Association for Community Living Delta Community Living Society Kelowna Community Development Society HRSDC UBC Dean of Arts

Please Join Us...

We welcome your feedback, ideas and support.

If you're an individual...

- Join one of our committees or working groups
- Volunteer for one of our events

If you're an organization....

- Consider partnering with us on a project
- Co-host a professional development event with us

The Centre needs your support to continue our work. **If you believe we have a valuable contribution to make, please consider becoming an organizational sponsor with an annual donation of \$750.** Contact Cindy Chapman at cic.ubc@ubc.ca or visit the website at www.cic.arts.ubc.ca to find out more. We'd be pleased to explore other ways we can mutually support each other to meet our collective needs and strengthen our movement.



Research with Relevance A Day with the Centre for Inclusion and Citizenship

British Columbia Association for Community Living Pre-Conference Day, May 30, 2012 Penticton Trade and Convention Centre

Research with Relevance is a one day event designed to inform, engage and inspire. The Centre for Inclusion and Citizenship invites you to join the conversation about how, together, we can create opportunities to identify, conduct, share, and apply research to promote the full inclusion of people with intellectual disabilities.

The day will include:

- An overview of why research is relevant; why we do it, ways we share it, and how we use it;
- Discussions on how research can increase organizational capacity; how you can collect and analyze information; and how to ensure the meaningful engagement of people with intellectual disabilities in research;
- Presentations on our latest research findings on Individualized Funding, Home Sharing, and Health and Healthcare for Older Adults with Intellectual Disabilities;
- Highlights of the Canadian Inclusive Lives Learning Initiative; and
- Opportunities to contribute to the development of a provincial research strategy we can undertake in partnerships to move us forward, steadfast and strong.

The participation of self advocates, families, students, service providers, educators, policy makers, and others is welcomed and encouraged.

Registration is now available at http://www.bcacl.org/conference-2012

Contact Us

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cic.ubc@ubc.ca www.cic.arts.ubc.ca 604-822-5872 **Dr. Tim Stainton,** Director

Dr. Rachelle Hole, Co - Director

Cindy Chapman, Centre Coordinator

Meaghan Feduck, Project Coordinator, (CILLI)

