

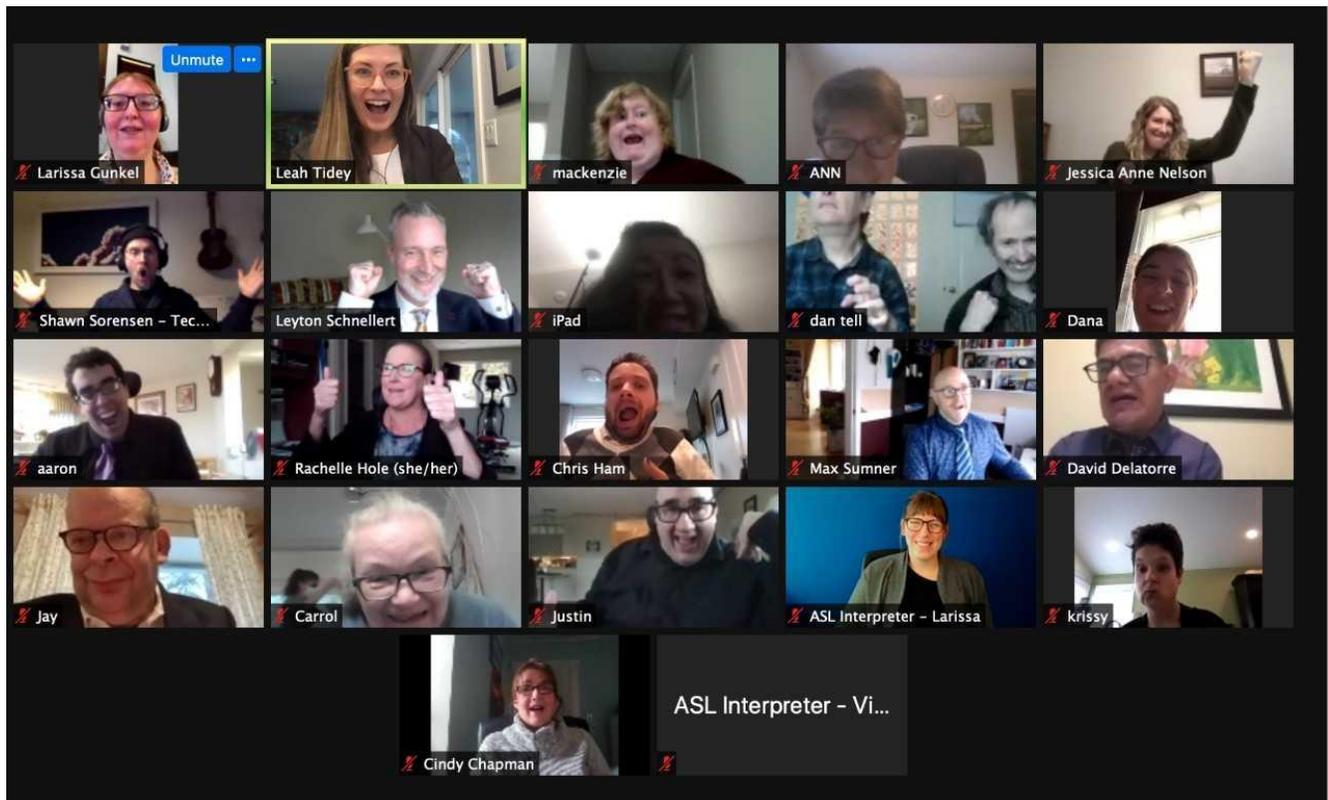


THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

# ANNUAL REPORT

## 2020 – 2021



*We Deserve to Work Theatre Project Zoom Session*

*We acknowledge that the UBC Okanagan campus is situated on the traditional, ancestral and unceded territory of the Syilx Okanagan Nation. We also acknowledge that the UBC Point Grey Campus is situated on the traditional, ancestral, and unceded territory of the Musqueam Peoples.*

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# Executive Summary

## Directors' Message

*Rachelle Hole & Tim Stainton*

Well we can truly say this year zoomed by! While disappointing that we were not able to meet in person with our many research and community partners, we were very pleased that the Institute's work continued to grow and we were able to contribute to the collective effort of battling COVID-19 through a number of research projects, publications, and consultative efforts. The CIIC's team of researchers undertook a number of research projects related to COVID-19 impacts on individuals with intellectual disabilities and their supporters who have borne a disproportionate amount of the many negative impacts of the pandemic. Perhaps most gratifying was the consultation, advice, and policy work the CIIC contributed to, working with a range of government and community partners such as our work supporting the advocacy efforts of Inclusion BC to ensure timely access to vaccines for people with intellectual disabilities. In many ways the pandemic helped us to demonstrate both the need for and the impact of our unique University-Community partnerships dedicated to supporting and enhancing the citizenship and inclusion of people with intellectual disabilities and their supporters.

While COVID-19 restricted our ability to travel, members of the Institute worked virtually across the country and internationally to further establish the Institute's reputation as Canada's leading University Institute for meaningful, scholarly, and community-engaged research and consultation on intellectual disability. The range of work documented in this report speaks to the growing breadth of our work and we are grateful to all of our academic, self-advocate, and community partners for their many contributions to our work.

We were also pleased to be able to support so many students through research and intern positions. This year we were able to offer three graduate internships on top of our regular research positions to help support students at both campuses. All three, Ramona, Clayton, and Brett have proven to be exceptional, undertaking a scoping review of the impacts of the pandemic on the disabled BIPOC community.

We have continued with core work such as TYDE, initiated a second phase of our very successful self-advocate led theatre initiative, and initiated a significant number of new projects detailed below. We were pleased to work with new partners such as the Sibling Collaborative as well as initiate new projects with long standing partners like Inclusion BC and Inclusion Canada. While the successful grants and publications are gratifying, as always, the real value and reward of our work is to continue to advance the cause of people with disabilities and their supporters, and we are very grateful for your trust in us as partners.

A huge thank you is due to our advisory board members old, new, and retiring who keep us on track and dedicate so much of their time to supporting us. Cindy Chapman continues to be the glue that

holds us together as our tireless coordinator and no amount of thanks will ever do justice to what she brings to the Institute. We'd also like to thank the UBC Okanagan Vice-Principal Research and Innovation and his team for their amazing support of the Institute and the School of Social Work and Faculty of Arts UBC Vancouver for their continued support.

We hope you will find this report on our work engaging. As always, please contact us if you'd like to get involved or have thoughts on our work. We look forward to another exciting and meaningful year ahead.

## **Message from the Provincial Advisory Board Chairperson**

*Dan Collins, Chief Executive Officer, Inclusion Langley Society*

There is a renewed sense of optimism among people as we begin to emerge from COVID-19 and the significant disruption it has brought to our day to day lives. It is gratifying to know that we can consider gathering again in person and reconnect with family, friends, and colleagues in safe ways, given the growing rate of vaccination we are seeing in our Province. I look forward to a future in-person gathering of the advisory board as this has been a key way to ensure research and life in community are explored together.

Many are acutely aware that the experience of this pandemic was not felt the same by everyone. People with intellectual and developmental disabilities were disproportionately impacted by the pandemic. Whether it was visitation policies in people's homes, essential supports while hospitalized or timely access to vaccine, the reality is that the voice of those very vulnerable to the virus and their allies was not always heard. This is where collaborative research can make a difference. Members of the Institute research team have been actively engaged in both research and policy consultation and advocacy on COVID-19. We are hopeful that their research will not only reveal the disparities but inform policy and practice improvements going forward. The voices of those most impacted by COVID-19 inform their research. Notwithstanding COVID-19, several key research initiatives progressed despite the added challenges.

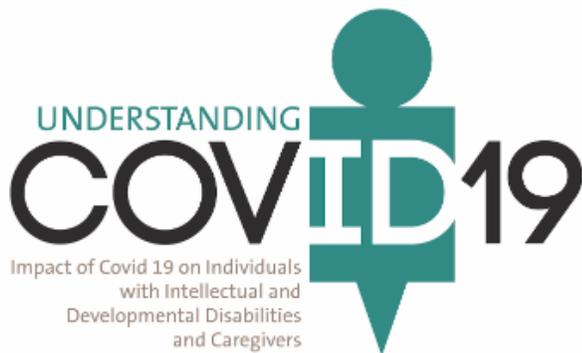
As always, the goal of the Institute is to be engaged at the community level in ways that ultimately inform and ensure knowledge translation. Research that influences policy and practice continues to shape and drive the activities and the work of the Institute and this year's annual report illustrates this. A sincere thank-you to the members of the advisory board who give of their time and talent. Thanks to those completing their time with the Institute and a warm welcome to new members. We are grateful for the growing numbers of UBC faculty shaping the agenda of the Institute and especially thankful for continued leadership from Tim, Rachelle, and Cindy.

## CIIC Responds to the COVID-19 Global Pandemic

COVID-19 has impacted our world in so many ways. Unfortunately it has hit the most vulnerable people hardest, including people with intellectual and developmental disabilities (IDD) and their families. The CIIC was quick to respond in a variety of ways to help mitigate the impacts and learn lessons for the future. Below are some of the ways we contributed to, and continue to respond to this global crisis.

### Research Projects

**COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers.**



Evidence suggests that people with intellectual and developmental disabilities experience disparities in healthcare access and utilisation. This disparity was evident early in the pandemic when discussions arose regarding the potential exclusion of this population to critical care. Drs Baumbusch and Stainton were pleased to be the Canadian leads for this international study including 19 countries. The survey collected over 5000 results overall and close

to 600 responses were gathered in Canada, the 3<sup>rd</sup> largest response rate of the 19 countries. Study findings will be prepared in a number of formats in order to meet the needs of different audiences. Outputs will include academic papers, lessons learned paper, practice guidelines, reports, infographics and video content. These outputs will be directed to families, frontline and management delivering disability services, national-level policy makers, healthcare quality and delivery authorities, national pandemic organisations and international bodies.

### The Impact of COVID-19 on BC's Children with Medical Complexity and their Families

Dr. Jennifer Baumbusch has shared the results of her survey about the impact of COVID-19 and associated restrictions on medically-complex children and their families in British Columbia. You can download a copy of the full report here: <https://spice.nursing.ubc.ca/outreach/>

A two-page infographic with some of the key information and recommendations is also available.

The results of the survey show that families are experiencing difficulties across multiple areas: healthcare usage (including access to medical specialists and therapies), education, and social services. The impact on parents/guardians is clear: over half of the respondents indicated that their physical and mental health have declined over the past year. The recommendations target ways to address these wide-ranging issues.

Please share this report widely. A recent CIHI report indicated that just under one percent of children are medically-complex. Families rely on leaders such as yourselves to help amplify their situation – a situation that was precarious before the pandemic and has now worsened.

## COVID-19: Understanding the Impact of COVID-19 on Inclusive Education for Students with Disabilities in British Columbia's Public Education (K-12) System

**Principal Investigator:** Jennifer Baumbusch

The overall goals of this project are to:

- understand the impact of COVID-19 on inclusive education for students with disabilities and complex learners in British Columbia's (BC) public education (K-12) system, and
- use this new knowledge to inform advocacy activities during subsequent waves of the pandemic, including informing hybrid models across online and in-person learning modalities to provide inclusive education.

### A Rapid Review of the Impacts of COVID-19 on BIPOC with Disabilities and their Networks

A CIIC project undertaken by UBC Social Work student interns Ramona Sharma, Clayton Marsh and Brett Mason supervised by Rachele Hole and Tim Stainton. Available on the CIIC website in September 2021.

### Publications

**Baumbusch, J.L.**, Lamden-Bennett, S.R., & Lloyd, J.E.V. (2020). *The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families*. Vancouver, BC: University of British Columbia. Available at: <https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0395118>

**Hole, R. & Stainton, T.** (Nov. 2020). COVID-19: The precarity of families & Disability. *Child and Youth Services*, 3. DOI: [10.1080/0145935X.2020.1834997](https://doi.org/10.1080/0145935X.2020.1834997)

Linehan C, Araten-Bergam T, **Baumbusch J, Stainton, T.** et al. (2020) COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. [version 2; peer review: 2 approved]. *HRB Open Res*, 3:39 (<https://doi.org/10.12688/hrbopenres.13077.2>)

Majnemer, A., McGrath, P.J., **Baumbusch, J.**, Camden, C., Fallon, B., Lunsky, Y., Miller, S.P., Sansone, G., **Stainton, T.**, Sumarah, J., Thomson, D., Zwicker, J. Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities. Royal Society of Canada. 2021. Available at: [https://rsc-src.ca/sites/default/files/IDD%20PB\\_EN\\_4.pdf](https://rsc-src.ca/sites/default/files/IDD%20PB_EN_4.pdf)

McGrath, Patrick; Majnemer, Annette; **Baumbusch, Jennifer**; Camden, Chantal; Fallon, Barbara; Lunsky, Yona; Miller, Steven; Sansone, Genevieve; **Stainton, Tim**; Thomson, Donna; Zwicker, Jennifer; Sumarah, John (2021). *Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities*. Royal Society of Canada. FACETS.

## Reports

**Stainton, Tim** (2021) [Considerations and Recommendations](#) for vaccine protocols and priority of people with intellectual and developmental disabilities and others receiving in home supports in individualized residential settings other than group homes or LTC facilities. CIIC. The report and recommendations are available on the CIIC website at the link above.

**Stainton, Tim** (2021) Covid-19 on a Global Scale (Canada) *Community Living*, Jan. 5 2021.

## Presentations

**Stainton, T.** June 25, 2020, IASSIDD-Disability Studies in the Netherland [Webinar](#) *New Eugenics and COVID-19*. International.

## Consultations

Stainton. **Consultation with National Disability Organizations on response to COVID-19**. March 2020.

Stainton. **Consultation with Inclusion BC, COVID-19/Vaccination Policy**. (Successfully lobbied for all persons eligible for CLBC to be included in Phase 2 of Vaccination schedule).

Stainton. Member, **Accessibility Legislation & COVID-19 Advisory Committee**, BC Ministry of Social Development and Poverty Reduction.

Stainton. Member. **Mental Health Research Canada's Proposal Review Panel** on a research initiative to mitigate COVID-19's impact on mental health. Provincial Partners: Saskatchewan, Ontario, New Brunswick and British Columbia. Research calls to mitigate COVID-19's impact on the mental health of children, youth and families in each jurisdiction.

## Media

**Baumbusch, Jennifer**. UBC nursing professor researching impact of COVID-19 on medically complex children. Vancouver Sun, April 11, 2020

**Stainton**. "Let me drive the bus"; People with disabilities want Covid reconstruction. June 4, 2020 . *Richochet Media*.

Matthias Hoben, Colleen Maxwell, Jennifer Baumbusch, David Hogan. Opinion: COVID's impact on assisted-living homes is being overlooked. Edmonton Journal. Nov 19, 2020

# Acknowledgements

**Congratulations to Dr. Jennifer Baumbusch** for being awarded the Canadian Institute of Health Research Sex & Gender Science Chair, Dynamics of Caregiving in an Aging Society (2020 – 2024). *Negotiating Care and Navigating Health Services: The Experiences of Community-dwelling People Living with Dementia and their Family Caregivers*. Dr. Baumbusch leads an applied research program examining the quality of care and quality of life of older Canadians and their family caregivers. She directs a research programme on health care delivery and nursing practice with older adults. Her focus is in long-term residential care, family contributions to care delivery, well-being among individuals with intellectual disabilities and their families, and knowledge translation. Dr. Baumbusch has expertise in critical ethnography and practice-close research and is committed to community-based research principles through active engagement of individuals, clinicians, service providers, and organizations.

**Sincere thanks to Kathleen Haggith and Dr. Karen Ragoonaden** who have stepped down from our Provincial Advisory Board. Kathleen has been a long-time contributor to the work of the institute with us since our early days as a research centre. She was an integral member of the advisory committee helping us to get established and represented the Provincial Human Services Public Deans and Directors Group. We were thrilled to have Karen come on board as the Co-Lead of the Inclusive Education research stream during our transition to the Institute. While we are sad to see her go, we wish Dr. Ragoonaden all the best in her new position as Dean of the Faculty of Education and the University of Manitoba and look forward to continued collaboration.

**A warm welcome to, Colton Sterling-Moses, Joshua Myers and Sue Sterling-Bur** who have joined the provincial advisory committee this year.

Colton is a young Indigenous man from the N'lakapmux and Syilx people in Merritt, BC. Colton is a pow-wow dancer, a traditional hand-drummer and a knowledge keeper for his Nations. He is a role-model and an advocate for Indigenous people and youth with disabilities. This past year Colton has been engaged with the TYDE project and participating in creating one of the videos for the *Confronting Misconceptions and Forging Pathways for Students with Disabilities* film project.

Joshua is the Executive Director of the BC Centre for Ability. The BC Centre for Ability was one of our first community partners and members of our original advisory board established in 2009. We are excited to welcome Josh who will add his expertise and experience serving children and youth and their families.

Sue is a PhD candidate in the UBC Okanagan, Interdisciplinary Studies Program – Indigenous Studies Theme. She is actively involved in our *Transitioning Youth with Disabilities to Employment* as a research assistant and the *Forging Pathways* Projects. Sue is also the Associate Vice President of Students at Nicola Valley Institute of Technology.

## Academic Measures

This report includes academic measures related to Intellectual and Developmental Disability research only. The CIIC Co-Directors, Research Leads and Co-Leads also conduct research, support student engagement, and produce knowledge outputs in other topic areas.

## Grants and Service Contracts

In 2020 - 2021, the CIIC undertook projects with a collective budget of \$3,835,748. New projects generated \$790,424 in new funding this reporting period and continued work on projects previously funded was in the amount of \$3,024,324. Researchers in **bold text** are CIIC Co-Directors, Research Leads and Co-Leads.

<b>Title</b>	<b>Remote Check-in Home Supports</b>		
<b>Funding Body</b>	Vancouver Foundation		
<b>Grant / Contract Total</b>	\$20,000 + \$10,000 partner cash	<b>Funding Period</b>	2020- 2021
<b>Principal Investigator(s)</b>	<b>R. Hole</b>	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Community Living Society (Lead Org.), Inclusion Langley Society, Richmond Society for Community Living, Spectrum Society for Community Living		
<b>Title</b>	<b>Advancing Equal Access for People with Intellectual Disabilities in the Workplace</b>		
<b>Funding Body</b>	Canadian Accessibility Standards Development Organization		
<b>Grant / Contract Total</b>	\$129,150	<b>Funding Period</b>	2020 - 2023
<b>Principal Investigator(s)</b>	<b>T. Stainton R. Hole</b>	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Inclusion Canada, People First of Canada		
<b>Title</b>	<b>Supporting the mental health needs of adults with developmental disabilities and their families during COVID-19: A national capacity building project</b>		
<b>Funding Body</b>	CIHR – COVID Mental Health and Addictions Operating Grant Competition		
<b>Grant / Contract Total</b>	\$199,996	<b>Funding Period</b>	2020- 2021
<b>Principal Investigator(s)</b>	Lunsky (NPI) Thakur (PI) Lake (PI) Durbin (PI)	<b>Co-Investigator(s)</b>	Hamdani, Y Thomson, K. McMorris, C. Bobbette, N. <b>Hole, R.</b> Sockalingam, Durbin, J. Hardy, J. Steel, L. Ries, H.
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Streisslberger (KU), Grier, L. (KU).		

<b>Title</b>	<b>Impact of COVID-19 on Individuals with Intellectual and Developmental Disabilities and Caregivers</b>		
<b>Funding Body</b>	Health Research Board Ireland		
<b>Grant / Contract Total</b>	62,858 Euros Approx \$92,278 CAD	<b>Funding Period</b>	2020 - 2021
<b>Principal Investigator(s)</b>	C. Linehan	<b>Co-Investigator(s)</b>	<b>T. Stainton</b> <b>J. Baumbusch</b> & 22 Co-Is Internationally
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>			
<b>Title</b>	<b>Supporting Siblings: A New Path to Financial Security</b>		
<b>Funding Body</b>	PLAN Canada		
<b>Grant / Contract Total</b>	\$14,000	<b>Funding Period</b>	2020 - 2021
<b>Principal Investigator(s)</b>	<b>T. Stainton</b> <b>R. Hole</b>	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Sibling Collaborative		
<b>Title</b>	<b>COVID-19: Understanding the impact of COVID-19 on inclusive education for students with disabilities in British Columbia's public education (K-12) system</b>		
<b>Funding Body</b>	Social Science and Humanities Research Council of Canada: Partnership Development Grant		
<b>Grant / Contract Total</b>	\$25,000	<b>Funding Period</b>	2020 - 2021
<b>Principal Investigator(s)</b>	<b>J. Baumbusch</b>	<b>Co-Investigator(s)</b>	Tracy Humphries BC EdAccess Partner Organization
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	J. Cannon, J.E.V. Lloyd, K. Verschoor, Inclusion BC		
<b>Title</b>	<b>We Deserve to Work! Self Advocates Transforming Attitudes About and Experiences with Employment</b>		
<b>Funding Body</b>	Vancouver Foundation Systems Change Grant		
<b>Grant / Contract Total</b>	\$300,000	<b>Funding Period</b>	2020 - 2023
<b>Principal Investigator(s)</b>	<b>R. Hole</b> <b>L. Schnellert</b>	<b>Co-Investigator(s)</b>	<b>T. Stainton</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Community Living Society, Massey Theatre		

<b>Title</b>	<b>IMPACT: Youth with Disabilities Employment Project</b>		
<b>Funding Body</b>	BC Ministry of Social Development and Poverty Reduction		
<b>Grant / Contract Total</b>	\$106,083	<b>Funding Period</b>	Jan 2020 – Dec 2022
<b>Principal Investigator(s)</b>	<b>R. Hole</b>	<b>Co-Investigator(s)</b>	C. Reid <b>T. Stainton</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Burnaby Association for Community inclusion, Chilliwack Society for Community Living, Community Living Victoria, Delta Community Living Society, Inclusion Langley Society, Possibilities, Richmond Society for Community Living, Unity WISE Employment Solutions		
<b>Title</b>	<b>Disrupting Misconceptions and Forging Pathways for Students with Developmental Disabilities</b>		
<b>Funding Body</b>	UBC Community- University Engagement Support Fund		
<b>Grant / Contract Total</b>	\$40,000	<b>Funding Period</b>	Jan 2020 – Jun 2021
<b>Principal Investigator(s)</b>	<b>R. Hole</b> <b>L. Schnellert</b>	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Inclusion BC		
<b>Title</b>	<b>Implementing Physical Activity Programs in Communities for Children with Neurodisabilities</b>		
<b>Funding Body</b>	Michael Smith Foundation for Health Research		
<b>Grant / Contract Total</b>	\$500,000	<b>Funding Period</b>	2019 - 2022
<b>Principal Investigator(s)</b>	<b>L. Olsen</b>	<b>Co-Investigator(s)</b>	W. Mc Kellin J.P. Collet. M. Gititmoghammad S. Glegg, T. Nault. <b>R. Hole</b> A. Miller W. McKee D. Whitehurst J. Tatarenko S. Moore S. McGinley G. Faulkner R. Weber H. Banack J. Zwicker
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Indigenous Sport and Physical Activity Council of BC, Special Olympics BC, Spirit of the Game Society, Sun Peaks Adaptive Ski Program, Victoria Native Friendship Society		

<b>Title</b>	<b>Assessing feasibility and effectiveness of an online parent resource to supportsafe and active sport and recreation for children with autism spectrum disorders</b>		
<b>Funding Body</b>	Social Sciences and Humanities Research Council		
<b>Grant / Contract Total</b>	\$120,440	<b>Funding Period</b>	2019 - 2022
<b>Principal Investigator(s)</b>	<b>L. Olsen</b>	<b>Co-Investigator(s)</b>	A. McManus <b>R. Hole</b> G. Iarocci M. Brussoni
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Autism Okanagan, Canucks Autism Network		
<b>Title</b>	<b>Vela Canada – Building Social Capitol – Intern Fellowship</b>		
<b>Funding Body</b>	Mitacs Canada		
<b>Grant / Contract Total</b>	\$65,000	<b>Funding Period</b>	2019 - 2021
<b>Principal Investigator(s)</b>	<b>T. Stainton</b>	<b>Co-Investigator(s)</b>	<b>R. Hole</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Vela Canada, Community Living British Columbia		
<b>Title</b>	<b>Transitioning Youth with Disabilities and Employment – The TYDE Project</b>		
<b>Funding Body</b>	CIHR / SSHRC Partnership Grant Awarded April 1, 2018		
<b>Grant / Contract Total</b>	\$2,320,324 (includes partner cash and in-kind contributions) CIHR/ SSHRC Funding: \$1,331,650	<b>Funding Period</b>	2018 - 2023
<b>Principal Investigator(s)</b>	<b>R. Hole</b>	<b>Co-Investigator(s)</b>	S. Barnes J. Bottorff C. Crawford J. Domene <b>L. Schnellert</b> <b>T. Stainton</b> R. Williamson A. Wise R. Young
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	BC Aboriginal Network on Disability Society, BC Centre for Employment Excellence, BC Council of Administrators of Inclusive Support, BC Employment Network, BC Ministry of Children & Family Development, BC People First, Community Living British Columbia, Family Support Institute of BC, Inclusion BC, Inclusion Canada, Simon Fraser University, University of Calgary		

## Student & Post Doctoral Supervision

### Post Doctoral Fellows

- Dr. Shelley Cook “Better Serving People with Multiple, Complex Needs in BC Through Health System Impact” Funding: CIHR Health Impact Post-Doc Fellow (2019 - 2021)

Dr. Shelley Cook is the recipient of the Health System Impact Fellowship from the Canadian Institute for Health Research with funding support from the Michael Smith Foundation for Health Research in BC and Community Living BC. The host partner is Community Living BC and the academic partner is UBC Okanagan.

The aim of this Health System Impact (HSI) fellowship is to better understand and address the health needs and service requirements of CLBC eligible adults who fall within the multiple, complex needs (MCN) framework. This population of people with life-long disabilities are not well served by existing services in BC, and little is known about their unique health needs/requirements. Owing to the complexity of their health and social issues, they crossover multiple services systems and are often high service users. Using a mixed methods design, the aim of this multi-phase research project is to better understand the health-related needs of this population and to identify/learn from emerging practice within BC and Canada.

- Sandra Marquis, PhD received a 3-year post-doctoral fellowship from the Michael Smith Foundation for Health Research for her project “Using Population-Level Administrative Health Data to Assess the Health of Youth who have a Developmental Disability as they Transition to Adult Health Services.” 2020 – 2023
- Dr. Leah Tidey  
Knowledge Translation for Romance Relationships and Rights (2020)  
We Deserve to Work! Theatre-based Research Project (2021)

Dr. Leah Tidey has her PhD in Applied Theatre from the University of Victoria. Dr. Tidey has been actively involved in our two theatre-based research projects: *Romance, Relationships, and Rights!* and *We Deserve to Work!* Dr. Tidey has been assisting with knowledge translation activities with Drs. Hole and Schnellert and supporting the theatre workshops for *We Deserve to Work!* as the stage manager.

### MSW Practicum Students

- Ramona Sharma, UBCO
- Lucia Woolgar, UBCO

## Graduate Student Internships

This year we were able to provide a \$1000 award and a unique opportunity for 3 MSW students to gain valuable experience supporting the work of the CIIC in a variety of research and other capacities. The students chose to conduct a study about the impact of COVID-19 on BIPOC with disabilities and their networks.

- Brett Mason, UBC Vancouver
- Clayton Marsh, UBC Okanagan
- Ramona Sharma, UBC Okanagan

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*I had a great experience and I appreciate having the opportunity to learn about the work of the CIIC. I also really appreciated having the opportunity to learn about how COVID was impacting people with disabilities and continue my research after the internship had concluded. Rachelle and Tim are also wonderful people to work with. I would highly recommend the internship for anyone who would like to learn more about people with intellectual and developmental disabilities. ~ Clayton Marsh*

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2021 Graduate Student Interns Ramona Sharma, Brett Mason, Clayton Marsh

## Additional Student Supervision

Student Name	Program Type	Topic	Supervisor	Committee Members
Belinda Chi	PhD Curriculum Studies - Education	Building employment for young adults with developmental disabilities	L. Schnellert	R. Hole
Bonny-Lynn Donovan	Ph.D. Interdisciplinary Studies -Community Engagement, Social Change & Equity	Exploring the Syilx's relationship with Land to inform education as a decolonizing practice	L. Schnellert	M. Evans J. Armstrong B. Cohen
Chinook McLean	M.A. Interdisciplinary Studies -Education	Creating transformative space entwining circles, restorative practices, and student voice	L. Schnellert	K. Ragoonaden R. Irwin M. McIntyre Latta
Crystal Shannon	IGS PhD Nursing	Recreation for children and youth with ASD and their families in ruraland remote communities	L. Olsen	R. Hole K. Rush
Fareed Mojab	PhD		T. Stainton	M. Ibrahim
Heather Beveridge	PhD	Disability Narratives and the Experience of Stigma in Uganda:Cultural Beliefs, Attitudes, Knowledge and Practices related to Cleft Lip and Palate (CLP)	T. Stainton	
Jennifer Anaquod	PhD - Curriculum Studies - Education	Learning from and with urban Indigenous Friendship Centres	L. Schnellert	S. Scott C. Ahenakew S. Leddy
Jennifer Christianson-Barker	PhD – Interdisciplinary Studies	Employment and the Business Case for Inclusive Hiring	R. Hole	T. Stainton L. Schnellert
Jewelless Smith	PhD – Interdisciplinary Studies	Understanding Systemic Barriers Across the Lifespan: A Human Rights Inquiry into Disability and Mothering.	R. Hole	L. Schnellert T. Stainton
Joann Anokwuru	Ph.D. Education – Curriculum Studies	Moving Toward the Ideal of Inclusive Education: A Narrative Inquiry of Being Disabled in Nigeria	L. Schnellert	K. Meyer B. Opini
Jodi Lee-Lewis	M.Ed. Curriculum Studies - Education	Engaging Educators through Culturally Sustainable Action & Inclusive Practice	L. Schnellert	
Kaan Goncu	PhD		T. Stainton	H. Kia
Kimberley MacNeil	Special Education PhD	Supporting teachers' professional learning through collaborative inquiry	D. Butler	L. Schnellert N. Perry
Kristan McOuat	M.Ed. Curriculum Studies - Education	Northern Middle Years Educators Creating Welcoming Environments for All Learners	L. Schnellert	
Leilani Forby	PhD - Psychology	Autism Spectrum Disorder and Mind Wandering	A. Kingstone	R. Hole

<b>Student Name</b>	<b>Program Type</b>	<b>Topic</b>	<b>Supervisor</b>	<b>Committee Members</b>
Lucia Woolgar	MSW Thesis	Mental Health Supports for Individuals with Intellectual Disabilities	<b>R. Hole</b>	<b>T. Stainton, Y. Lunsky</b>
Mary Kjørven	IGS PhD Nursing	A post-structural autoethnography on the dual roles of nursing expert and a family member	K. Rush	<b>R. Hole C. Reid J. Baumbusch</b>
Megan Zeni	Curriculum Studies - Education	Understanding barriers and expanding opportunities for outdoor play and learning in the elementary school context	<b>L. Schnellert</b>	M. Brussoni H. Keenan
Meredith Rusk	Ph.D. Interdisciplinary Studies - Education	Validating Indigenous Knowledge in Educators' Practices and Minds	<b>L. Schnellert</b>	M. Evans V. Magnat <b>K. Ragoonaden</b>
Michelle Hewitt	IGS PhD	Long term care and residential options for younger adults with disabilities	<b>R. Hole</b>	<b>T. Stainton C. Reid</b>
Miriam Miller	Ph.D. Human Development, Learning and Culture	Fostering Social and Emotional Development	<b>L. Schnellert</b>	S. Hymel D. Butler
Nadia Galvan Hernandez	Ph.D. Interdisciplinary Studies -Community Engagement, Social Change & Equity	Disability Justice and Community Art Practice	<b>L. Schnellert</b>	<b>R. Hole</b>
Paige Reeves	PhD	On the Margins: People with Intellectual or Developmental Disability Negotiate Belonging within Ableist Community		<b>T. Stainton</b>
Rae Morris	PhD	Mental health service provision with adults with autism spectrum disorder: An interpretive description study	<b>T. Stainton</b>	
Ramona Sharma	MSW	ADHD, Cannabis, and Academic Success	<b>R. Hole</b>	Z. Walsh S. Dow-Fleisner
Sarah Martin	MA Interdisciplinary Studies -Community Engagement, Social Change & Equity	Community-Based Indigenous Food Systems	<b>R. Hole L. Schnellert</b>	
Shelly Moore	Ph.D. Cross-Faculty Inquiry in Education	Transforming Inclusive Education for Students with Intellectual Disabilities in Secondary School	<b>L. Schnellert</b>	D. Butler J. Lucychyn

### Visiting Scholar (UBC Vancouver School of Social Work)

- Ji Lixin, Shandong University

## Publications, Reports, Presentations and Videos

April 2020 – March 2021. CIIC researchers are highlighted in **bold**; students are underlined.

### Publications

Battalova, A., Bulk, L., Nimmon, L., **Hole, R.**, Krupa, T., Lee, M., Yael, M. & Jarus, T. (May 2020). "I can understand where they're coming from." How clinicians' disability experiences shape their interaction with clients. *Qualitative Health Research*, 30 (13), 2064-2076.

<https://doi.org/10.1177%2F1049732320922193>

**Baumbusch, J.**, Lloyd, J.E.V., Liou, Y.C.D., & Zou, D. (2020). Educational leaders' perspectives on special education research: a priority setting study. *International Journal of Education Policy and Leadership*, 16(15), 1-15

Breau, G.M., **Baumbusch, J.**, Thorne, S., Hislop, T.G., & Kazanjian, A. (2021). Primary care providers' attitudes towards individuals with intellectual disabilities: associations with experience and demographics. *Journal of Intellectual Disabilities*, 25(1), 65-81. doi: 10.1177/1744629519860029

Breau, G.M., Thorne, S., **Baumbusch, J.**, Hislop, T.G., Kazanjian, A. (2020). Primary care providers' attitudes towards recommending cancer screening to patients with intellectual disability: A cross-sectional survey. *Inclusion*, 8(3), 185-193. doi: [/10.1352/2326-6988-8.3.185](https://doi.org/10.1352/2326-6988-8.3.185)

Cook, S. & **Hole, R.** (accepted, Mar. 18, 2021). Trauma intellectual disabilities and multiple complex needs: A scoping review of the literature. *Research in Developmental Disabilities*. <https://doi.org/10.1016/j.ridd.2021.103939>

Cook, S., & **Hole, R<sup>SR</sup>**. (May 2020). "Appropriately homeless and needy": Examining street homeless survival through the lens of Bourdieusian social capital theory. *Journal of Human Behavior in the Social Environment*, 30 (7), 816-834. DOI: 10.1080/10911359.2020.1747585

Curle, D. El Bouhali, A. Ma, Z. Marshall, S. Murray, J. Parada, F. **Stainton, T.** Wall, J. Wu, S. & Young, R.(2020) Transition to adulthood for individuals with intellectual disability'. In E. Anne Marshall & Jennifer E. Symonds Eds. *Young Adult Development at the School-to-Work Transition*. Oxford: Oxford UP. (Co-investigator on research project 15%). First published: 23 Jun 2020, 3:39 <https://doi.org/10.12688/hrbopenres.13077.1>

**Hole, R. & Stainton, T.** (Nov. 2020). Covid 19: The precarity of families & Disability. *Child and Youth Services*, 41 (3), 266 - 268. DOI: [10.1080/0145935X.2020.1834997](https://doi.org/10.1080/0145935X.2020.1834997)

Linehan C, Araten-Bergam T, **Baumbusch J, Stainton, T.** et al. (2020) COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. [version 2; peer review: 2 approved]. *HRB Open Res*, 3:39 (<https://doi.org/10.12688/hrbopenres.13077.2>)

Lloyd, J.E.V, **Baumbusch, J.L.**, & Zou, D. (2021). Community lives of adolescents across multiple special needs: Discrimination, community belonging, trusted people, leisure activities, and friends. *Journal of Community Psychology*, 49(5), 1393-1417. doi: 10.1002/jcop.22498

Lloyd, J.E.V., Zou, D., & **Baumbusch, J.L.** (2020). Sociodemographic profiles of high school students across multiple types of special needs and disabilities. *Journal of Research in Special Educational Needs*, 20(4), 279-290. doi: [10.1111/1471-3802.12488](https://doi.org/10.1111/1471-3802.12488)

Macintyre Latta, M., **Schnellert, L.**, **Ondrik, K.**, & Sasges, M. (2020). Modes of being: Mobilizing narrative inquiry. *Qualitative Inquiry* 26(10), 1222-1232. <https://doi.org/10.1177/1077800418786309>

McGrath, Patrick; Majnemer, Annette; **Baumbusch, Jennifer**; Camden, Chantal; Fallon, Barbara; Lunsky, Yona; Miller, Steven; Sansone, Genevieve; **Stainton, Tim**; Thomson, Donna; Zwicker, Jennifer; Sumarah, John (2021). *Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities*. Royal Society of Canada. FACETS

Reinders, J. , **Stainton, T.** and Parmenter, T. R. (2020) Disposable Lives: Is Ending the lives of Persons with Intellectual and Developmental Disabilities for Reasons of Poor Quality of Life an Emergence of a New Eugenics Movement. In Prasher, Davidson, Santos Eds., *Mental Health, Intellectual and Developmental Disabilities and the Aging Process*. 2nd Edition. Springer Nature

Young, R.A., Marshall, S.K., **Stainton, T.**, & Chi, E. (2020) Transition to adulthood: prospective content in joint parent-youth conversations for young people with intellectual or developmental disabilities (IDD), *International Journal of Developmental Disabilities*, DOI: [10.1080/20473869.2020.1827212](https://doi.org/10.1080/20473869.2020.1827212)

**Schnellert, L.** (2020). Exploring the potential of professional learning networks. In Schnellert, L. (Ed.) *Professional learning networks: Facilitating transformation in diverse contexts with equity-seeking communities*. Bingley, UK: Emerald Publishing, 1-15

**Schnellert, L.**, & Butler, D.L. (2020) Exploring the potential of collaborative teaching nested within professional learning networks. *Journal of Professional Capital and Community* 6 (2). 99-116. <https://doi.org/10.1108/JPCCC-06-2020-0037>

**Shannon, C.A.**, **Olsen, L.L.**, **Hole, R.**, Rush, K.L. (2021) “There’s nothing here”: Perspectives from rural parents promoting safe active recreation of children living with autism spectrum disorders. *Research in Developmental Disabilities*, 115 (2021). doi: 10.1016/j.ridd.2021.103998. Epub 2021 Jun 7

**Shannon, C.A.**, **Olsen, L.**, **Hole, R.**, Iarocci, G., Brussoni, M., & Jull, S. (March 2021). Community engagement in web-design to promote safe recreation for children with autism. *Injury Preventing*, 27 (Suppl 2). <http://dx.doi.org/10.1136/injuryprev-2021-safety.205>

## Commissioned Reports

Majnemer, A., McGrath, P.J., **Baumbusch, J.**, Camden, C., Fallon, B., Lunsky, Y., Miller, S.P., Sansone, G., **Stainton, T.**, Sumarah, J., Thomson, D., Zwicker, J. *Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities*. Royal Society of Canada. 2021. Available at: [https://rsc-src.ca/sites/default/files/IDD%20PB\\_EN\\_4.pdf](https://rsc-src.ca/sites/default/files/IDD%20PB_EN_4.pdf)

**Stainton, Tim** (2021) Considerations and Recommendations for vaccine protocols and priority of people with intellectual and developmental disabilities and others receiving in home supports in individualized residential settings other than group homes or LTC facilities. CIIC

Inclusion Canada, People First of Canada, and the UBC’s Canadian Institute for Inclusion and Citizenship [Co-author (**Hole**)] (March 15, 2021). Response to draft general comment no. 8 Article 27: The right to work and employment of the UN Convention on the Rights of Persons with Disabilities.

**Stainton, Tim** (2021) Covid-19 on a Global Scale (Canada) *Community Living*, Jan. 5 2021.

## Research Reports

**Hole, R.,** Reid, C., & **Mudde, L.** (January 29, 2021). IMPACT Cohort 1 Evaluation. *Ministry of Social Development and Poverty Reduction & The BC Employment Network*. 44 pages

**Hole, R., Stainton, T., Metcalfe, R., Woolgar, L.** (March 2021). Future planning and sibling carers of individuals with intellectual and developmental disabilities. Submitted to the Planned Lifetime Advocacy Network and the Sibling Collaborative

**Baumbusch, J.L.,** Lamden-Bennett, S.R., & Lloyd, J.E.V. (2020). *The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families*. Vancouver, BC: University of British Columbia. Available at [:https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0395118](https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0395118)

Lloyd, J.E.V. & **Baumbusch, J.L.** (2020). *Inclusive education snapshot: prevalence over time of BC's K-12 students with learning exceptionalities and disabilities*. Vancouver, BC: University of British Columbia. Available at: <https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0392710>

## Films Produced (non peer-reviewed)

*Disrupting Misconceptions and Forging Pathways for Students with Disabilities*. Funded by the UBC CUES Fund (**Hole and Schnellert Co-PIs and Producers in partnership with Inclusion BC**):

Four films: Available at <https://cic.arts.ubc.ca/research-streams/inclusive-education/projects/>

- Film 1: Exercising Self Determination in our Schools
- Film 2: Reframing Challenging Behaviour in our Schools
- Film 3: Getting Ready to Work in our Schools
- Film 4: Indigeneity and Disability in our Schools

## Publications Submitted

**Hole, R., Schnellert, L., & Tidey, L.** (in review). *Romance, Relationships and Rights: Ethical Considerations and Dilemmas in a Research-Based Theatre Project with Self-Advocate Co-creators and Actors*. *Qualitative Inquiry*

**Schnellert, L., Tidey, L., & Hole, R.**<sup>SR/PI</sup> (Accepted). "You have the right to love and be loved": Participatory theatre for disability justice with self-advocates. *Qualitative Research*. Thousand Oaks, CA: SAGE

## Conference and Invited Presentations, Podcasts and Webinars

**Hole, R.,** Figuera, J., Rosal, S., & Sterling-Moses, C. (Feb. 19, 2021). Keynote: Creating pathways to employment: Celebrating successes and overcoming challenges. The TYDE Project. *Inclusion BC Youth Employment Summit*. British Columbia

**Hole, R., Schnellert, L., & Cante, G.** (2020 July). Sex! What's the big deal? Promoting sexual health, romance, relationships, and rights! Congress 2020: International Association for the Scientific Study of Intellectual and Developmental Disabilities. Toronto, Ont., Canada. [Conference cancelled due to COVID-19]

**Mudde, L., Reid, C., & Hole, R** <sup>PI/SR</sup> (November 26, 2020). *IMPACT: Preliminary results for Cohort 1*. Presented to the BC Employment Network

**Olsen, L., Shannon, C.A.,** Thompson, D., Balehowsky, C. (2021, March). Scoping review of elopement behavior among children with autism. Virtual Pre-Conference Global Injury Prevention Showcase 2021, Adelaide, Australia. (Virtual poster presentation)

**Schnellert, L.** (January 2021). Why is student agency important in an IEP? <https://blogsomemoore.com/icbiep-session-3-2/>. Inclusive and Competency Based IEPs webinar series. Host: Shelley Moore

**Schnellert, L.** (June 2020). <https://quaranteachin.souder.fm/episode/episode-4-leyton-schnellert>. Quaranteachin' Podcast. Hosts: Thomas Skelton, Katie de Bruycker, & Sam Stremecki

**Schnellert, L.** (2020, Apr 17 - 21) *Drawing on student funds of knowledge in professional learning networks to increase success for equity-seeking learners*. AERA Annual Meeting San Francisco, CA <http://tinyurl.com/tggzwa>. (Conference Cancelled)

**Schnellert, L., Ondrik, K. & Kozak, D.** (November 2018). Don't SHOULD on Me! <https://podcast.app/dont-should-on-me-leyton-schnellert-kim-ondrik-donna-kozak-e44227718/>. The Five Moore Minutes Podcast. Host: Shelley Moore

**Schnellert, L., & Butler, D.L.** (2021, April). Exploring the potential of co-teaching nested in professional learning networks. Invited paper presented in the Knowledge mobilization in professional learning networks symposium at the annual meeting of the American Educational Research Association. Online

**Shannon, C., Olsen, L.,** Janke, R., Balehowsky, C. (Nov, 2020). Scoping review of eHealth resources for parents of children living with autism spectrum disorders. Kids Brain Health (KBHN) Virtual Conference, Annual Conference, 2020. (Virtual poster presentation)

**Shannon, C.A., Olsen, L.L., Hole, R.,** Iarocci, G., Brussoni, M., Jull, S (2021, March). Community engagement in web-design to promote safe recreation for children with autism. Virtual Pre-Conference Global Injury Prevention Showcase 2021, Adelaide, Australia.(Virtual poster presentation)

**Stainton, T.** June 25, 2020, IASSIDD-Disability Studies in the Netherland Webinar 'New Eugenics & COVID-19'. International

Taylor, T., & **Schnellert, L.** (2021, March) Educational transformation through an equity lens: Collaborating to engage all learners. International Congress on School Effectiveness and Improvement. Online

## Media

**Stainton, T.,** Interview, '[Question Mark: Conversations about philosophy and ethics](#)' Youtube Ch. On Bill C7 – Medical Assistance in Dying (MAiD) in Canada. March 5<sup>th</sup> 2021

"*Leap makes an IMPACT this summer*". Connections Newsletter – Delta Community Living Society. <https://www.dcls.ca/admin/files/96644dclsnewsletterfall2020digital.pdf> Hole PI, funded by the BC Ministry of Social Development and Poverty Reduction

# Research Streams & Project Descriptions

## Research Streams

Four research streams inform the work of the Institute at present and we intend to add a fifth research stream focusing on promoting and conducting I/DD research with Indigenous communities and families within the next three years.

### Policy, Practice and Ethics

**Primary Lead: Dr. Tim Stainton – School of Social Work, Faculty of Arts, UBC Vancouver**

**Co-Lead: Dr. Rachelle Hole – School of Social Work, Faculty of Health and Social Development, UBC Okanagan**

This stream has a broad focus on issues concerned with policy, structures, and direct practice in the field. This encompasses both Provincial (the primary responsible jurisdiction) and National policy and practice in Canada as well as international policy and practice developments. While issues directly affecting people with I/DD and their families will be the core focus, this stream will also extend to health care practices, which may impact people with I/DD as well as global issues such as the implementation of the UN Convention on the Rights of Persons with a Disability. Dr. Stainton is ideally suited to lead this stream having been recognized for many years as one of the leading international experts in this area and having consulted with governments and organization across Canada and internationally.

### Employment and Transitions

**Primary Lead: Dr. Rachelle Hole – School of Social Work, Faculty of Health and Social Development, UBC Okanagan**

**Co-Lead: Dr. Tim Stainton – School of Social Work, Faculty of Arts, UBC Vancouver**

Employment is a key aspiration for individuals with I/DD and a key priority of the community living sector. Research demonstrates that employment enhances quality of life for most working-age adults and is a key mechanism for enhancing social inclusion. This research stream focuses on improving employment outcomes for individuals with I/DD with an additional focus on transitioning youth. Intervening early is key to improving employment outcomes for individuals with I/DD.

## Health and Well-being of Individuals with Intellectual and Developmental Disabilities and their Families Across the Life-Course

**Primary Lead: Dr. Jennifer Baumbusch – School of Nursing, Faculty of Applied Science, UBCVancouver**

**Co-Lead: Dr. Lise Olsen – School of Nursing, Faculty of Health and Social Development, UBCOkanagan**

It is well documented that individuals with intellectual and developmental disabilities and their families experience health inequities across the life-course. This research cluster aims to illuminate socio-political and structural factors that contribute to inequities. This research will help to inform ethical and equitable policies and practices that support health and well-being across the life-course.

## Inclusive Education

**Primary Lead: Dr. Leyton Schnellert – Faculty of Education, UBC**

**Co-Lead: Dr. Karen Ragoonaden – Faculty of Education, UBC Okanagan** (until December 2020)

The Inclusive Education research stream is comprised of university faculty, educators, self advocates, and family members deeply committed to enacting and furthering inclusive education. This research stream is comprised of people with expertise in diverse research methodologies, theoretical approaches, and educational structures, practices, and pedagogies. We seek to mobilize and generate knowledge that supports the inclusion of students with I/DD through intersectional approaches that leverage potentialities across cognitive, sensory, cultural, gender, sexual orientation, and gender identity diversities.

## Working with Indigenous Communities and Families and I/DD

We are committed to formalizing an explicit research stream focused on I/DD research with Indigenous communities and families in the next 2 years.

## Research Project Descriptions & Selected Highlights

Please see Page 5 for a summary of work in response to COVID -19

### Disrupting Misconceptions and Forging Pathways for Students with Developmental Disabilities Funded by UBC Community Engagement in partnership with Inclusion BC.



Increasingly students with developmental disabilities are facing discrimination and stigma in school. Extensive media attention has been given to “behaviour” of students that is deemed unsafe. Students are being excluded from classrooms and ostracized in their communities. Organizations from the United Nations to parent advocacy groups are calling

for action to recognize students with developmental disabilities as full citizens with the right to education. This collaboration created four short films raising awareness about the exclusion of students with developmental disabilities and offering key information and possible pathways to success for families and schools.

- Film 1: Exercising Self Determination in our Schools
- Film 2: Reframing Challenging Behaviour in our Schools
- Film 3: Getting Ready to Work in our Schools
- Film 4: Indigeneity and Disability in our Schools

In partnership with Inclusion BC, the films were released during Inclusive Education Month in February 2021 and launched with a free online webinar featuring project partners. Please view the films at <https://cic.arts.ubc.ca/research-streams/inclusive-education/projects/>

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*When we began this project we had no idea what an impact on our own lives (it would have) and I know I speak for all of us when I say that our lives are forever changed; We have learned so much and grown even more. So thank you!*

*~ Neil A. Ferguson. One Island Media, Inc (Project Videographer)*

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### Implementing Physical Activity Programs in Communities for Children with Neurodisabilities

Funded by Michael Smith Foundation for Health Research. Implementation Science Team Grant

Few physical recreation programs exist for children with neurodevelopmental challenges, particularly in rural settings and in Indigenous communities. This project's goal is to study the implementation of a new physical activity coaching approach (NPAC) for children with neurodevelopmental challenges and their families.

## We Deserve to Work

Funded by the Vancouver Foundation, in partnership with the Community Living Society and Massey Theatre.

People with intellectual and developmental disabilities want to work, and research demonstrates they are great employees (UBC CIIC, 2018). Policy makers, practitioners, family members, and self-advocates are calling for improved employment outcomes for individuals with IDD. People with IDD deserve competitive integrated employment: a career in the open labour market with non-disabled employees that offers at least minimum wage and similar benefits to all colleagues, including opportunities for growth.

Through social theatre we will problematize and transform societal misperceptions and stereotypes by celebrating self-advocates' abilities and right to work. This project will tackle this complex social issue and challenge employers to learn about the benefits of inclusive hiring. Moreover, this project aims to increase awareness about the rights to employment for self-advocates among family members, support workers, employers, and individuals with IDD themselves. Self-advocates deserve to work! This project is building on the success of the Romance, Relationships and Right Participatory Theatre project.



*Vancouver Foundation Application Consultation*



## Advancing Equal Access for People with Intellectual Disabilities in the Workforce

Funded by Canadian Accessibility Standards Development Organization.

In partnership with Inclusion Canada and People First Canada over 3 years, we are undertaking research on behalf of the new Federal body Accessibility Standards Canada to look at what standards will help to facilitate employment of people with an intellectual disability. Our work includes conducting a Literature Review surrounding employment accessibility standards and guidelines for people with intellectual disabilities; preparing a Jurisdictional Analysis of current employment accessibility standards and barriers for people with intellectual disabilities throughout the four key cycles of employment; and designing, delivering and analysing key informant interviews and an online survey in English and French for self advocates, employment specialists and employers. We will use this information to prepare a Knowledge Synthesis Report on barriers, best practices and guidelines for people with intellectual disabilities throughout the four key cycles of employment. This will be shared for discussion at focus groups throughout the country to review and validate research findings and prioritize with respect to the development of standards.

## Impact - Youth Employment Research Project

Funded by the BC Ministry of Social Development and Poverty Reduction and in partnership with the BC Employment Network.

This project tests the hypothesis that intervening early with transitioning youth using employment interventions that consider each individual's unique strengths and interests will improve future employment outcomes for transitioning youth. Eight youth serving agencies are in their second year on implementing summer job opportunities. Preliminary outcomes from Year 1 reveal an increase in overall paid and unpaid work experience through engagement with IMPACT, as well as increase in some MAS employability domains and self-assessed knowledge about employment. Sixty of the youth participated in unpaid work experience and 26 got paid employment while participating in IMPACT. The project report from year 1 can be found on the [project page](#).

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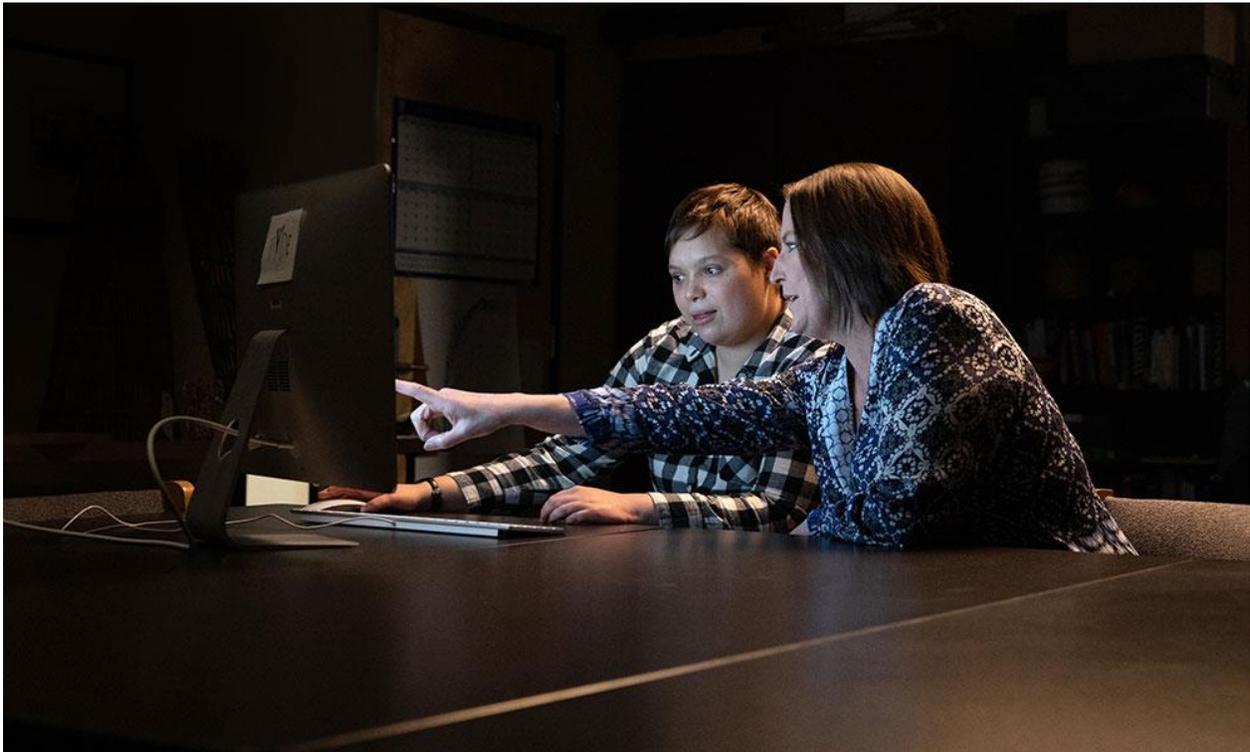
*Findings from Cohort 1 reveal that the intervention for youth with developmental disabilities using an agency specific tailored approach improves the youth's unique strengths and interests related to employment and skills.*

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**Transitioning Youth with Disabilities and Employment (TYDE) [www.mytyde.ca](http://www.mytyde.ca)**

Funded by Social Sciences and Humanities Research Council and Canadian Institute for Health Research, and with Community and Government Partners.

This project is an interdisciplinary, cross-sectoral network of partners committed to improving the employment outcomes for transitioning youth ages 14 – 18 with intellectual disabilities or autism in British Columbia through early an intervention targeting youth and their parents/caregivers. Through this partnership, we are creating an interactive online curriculum to increase employment outcomes for youth with developmental disabilities by increasing youth pre-employment skills, increasing youth self-determination, and improving parental/caregiver knowledge and expectations for fostering their youth’s future employment experiences. Cohort 2 is scheduled to be piloted with 4 school districts beginning in the Fall of 2021.



*Shameera Rosal with Rachelle Hole*

# Team Members

## Co-Directors

- Dr. Rachelle Hole, Associate Professor, Social Work, Faculty of Health and Social Development, UBC Okanagan
- Dr. Tim Stainton, Professor, School of Social Work, Faculty of Arts, UBC Vancouver

## Research Leads and Co-Leads

- Dr. Jennifer Baumbusch, Associate Professor, School of Nursing, UBC Vancouver
- Dr. Karen Ragoonaden, Professor of Teaching, Okanagan School of Education, UBC (until Dec 2020)
- Dr. Leyton Schnellert, Associate Professor, Faculty of Education, UBC
- Dr. Lise Olsen, Associate Professor, Faculty of Health and Social Development, School of Nursing, UBC Okanagan

## Research Affiliates/Collaborators

- Dr. Alison McManus, Professor, Health and Exercise Science, UBC Okanagan
- Dr. Colin Reid, Health and Exercise Sciences, UBC Okanagan
- Dr. David Whitehurst, Faculty of Health Science, Simon Fraser University
- Dr. Elizabeth Anderson, School of Nursing, UBC Vancouver
- Dr. Grace Iarocci, Director of Clinical Training, Department of Psychology, Simon Fraser University
- Dr. Guy Faulkner, School of Kinesiology, UBC
- Dr. Hartley Banack, Faculty of Education, UBC
- Dr. Ian Pike, Investigator, BC Children's Hospital Research Institute, Faculty of Medicine, UBC
- Dr. Jean-Paul Collet, Department of Pediatrics, Faculty of Medicine, UBC
- Dr. Jill Zwicker, Department of Occupational Science & Occupational Therapy, UBC
- Dr. Joan Bottorff, Director, Institute for Healthy Living and Chronic Disease Prevention, UBC Okanagan
- Dr. Jose F. Domene, Werklund School of Education, University of Calgary,
- Dr. Mariana Brussoni, Investigator, BC Children's Hospital, Academic Scientist, BC Injury Research & Prevention Unit
- Dr. Michael Weymeher, University of Kansas
- Dr. Mojgan Gitimoghaddam, University of British Columbia
- Dr. Rachel Weber, Faculty of Education, UBC
- Dr. Richard Young, Counselling Psychology, UBC Vancouver
- Dr. Robert Williamson, Faculty of Education, Simon Fraser University
- Dr. Sarah Moore, Therapeutic Recreation, Douglas College
- Dr. Stephanie Glegg, Sunny Hill Health Centre
- Dr. Steven J. Barnes, Co-Director, Collaborative REsearch Team (CREST.BD), UBC Vancouver
- Dr. William H McKellin, Department of Anthropology, University of British Columbia

- Dr. William McKee, School of Psychology & Special Education, UBC
- Dr. Yona Lunsky, Director of the Azrieli Adult Neurodevelopmental Centre, Senior Scientist in the Adult Neurodevelopment and Geriatric Psychiatry Division, and Director of the Health Care Access Research and Developmental Disabilities (H-CARDD) Program at CAMH
- Jean Tatarenko, Competition & Youth Coordinator. Special Olympics, BC
- Lois McNary, Special Olympics BC
- Steve McGinley, Faculty of Education, UBC
- Tara Nault, Indigenous Sport, Physical Activity & Recreation Council, BC

## Research Assistants and Staff

### Research Assistants/Students and Work Study Students

- Celeste Borja, MSW, Microboards and Social Capital Project
- Emily Giroux, PhD, TYDE Project
- Jenna Christianson-Barker, MSW, Advancing Equal Access for People with Disabilities in the Workforce and We Deserve to Work Projects
- Jennifer Kwok, BA, Work Study, TYDE Project
- Laura Mudde, PhD, IMPACT Project
- Leilani Forby, MA/PhD, Work Study, TYDE Project
- Lucia Woolgar, MSW, Advancing Equal Access for People with Disabilities in the Workforce Project
- Rae Morris, PhD, Microboards and Social Capital Project
- Ramona Sharma, MSW, Advancing Equal Access for People with Disabilities in the Workforce Project
- Robin Metcalfe, MSW, TYDE Project
- Sandra Polushin, PhD (Simon Fraser University), TYDE Project (UBC GAA)
- Sue Sterling-Bur, PhD Candidate – TYDE Project; Disrupting Misconceptions and Forging Pathways for Students with Developmental Disabilities Project

### Research Staff

- Aidin Niavarani, Application Lead Developer, TYDE Project

### Project Contractors

- Jessica Ann Nelson, Romance, Relationships & Rights, Co-Producer / Co-Director
- One Island Media
- Suzie Giroux, American Sign Language (ASL) Interpreter, We Deserve to Work Project
- Vicki Yee, American Sign Language (ASL) Interpreter, We Deserve to Work Project

### Staff

- Rachel Aizen, Administrative Support
- Cindy Chapman, CIIC Coordinator

## Self Advocate Consultants

The Institute makes every effort to include self advocates in all areas of research from project conception and design, to developing plain language research summaries, and in participating in knowledge translation/knowledge mobilization activities (e.g., conference co-presenters). Many individuals who identify as having a developmental disability have contributed to our initiatives in paid positions whenever possible

- Aaron Pietras, We Deserve to Work Project
- Colton Sterling-Moses, TYDE Project, Provincial Advisory Committee
- Dale Froese, Time to be Counted Covid-19 Royal Society Project
- Dana Faris, We Deserve to Work Project
- Jake Anthony, Time to be Counted Covid-19 Royal Society Project
- Joanne Gauthier, Social Capital Project, Time to be Counted Covid-19 Royal Society Project
- Jose Figueroa, TYDE Project
- Kaitlin Smith, TYDE Project
- Kara Anderson, Time to be Counted Covid-19 Royal Society Project
- Kyle Youmans, TYDE Project
- Larissa Gunkel, We Deserve to Work Project
- Leanne Froese, Time to be Counted Covid-19 Royal Society Project
- Michael McLellan, Social Capital Project, Time to be Counted Covid-19 Royal Society Project
- Shameera Rosal, TYDE Project

A special thank you to the self advocates who were interviewed for the four Inclusive Education Videos.

# Governance

## Provincial Advisory Board

The provincial advisory board offers advice to the Institute, assists with fund development, ensures information flows between community and the university, informs research priorities, assists in the design and implementation of projects, facilitates the communication of results, and helps to evaluate application and uptake of the results. The membership includes a minimum of two individuals with I/DD (self advocates), family members, service providing agencies, provincial advocacy organizations, and one representative each from the Faculty of Health and Social Development at UBC Okanagan and the Faculty of Arts at UBC Vancouver.

### Provincial Advisory Board Members 2020 – 2021

- Dan Collins, Inclusion Langley Society, Chair
- Angela Clancy, Family Support Institute of BC
- Colton Sterling-Moses, Self Advocate Consultant
- Jack Styan, Community Living BC
- Janice Barr, Community Living Society
- Jason Gordon, BC Association for Child Development and Intervention
- Joanne Gauthier, BC People First
- Joshua Myers, BC Centre for Ability
- Karla Verschoor, Inclusion BC
- Kathleen Haggith, North Island College
- Sue Sterling Bur, UBC Okanagan Graduate Student
- Rachelle Hole, CIIC, UBC Okanagan
- Tim Stainton, CIIC, UBC Vancouver
- Faculty of Health and Social Development, UBC Okanagan (Representative TBD)
- Faculty of Arts, UBC Vancouver (Representative TBD)

## Space

### UBC Okanagan

The Canadian Institute for Inclusion and Citizenship shares space with the Institute for Community Engaged Research at UBC Okanagan. There is one office space for Dr. Rachelle Hole, three work stations, and a board room. This past year CIIC researchers, students, and staff at UBCO worked remotely from home due to COVID-19.

### UBC Vancouver

The CIIC Coordinator has been working remotely due to Covid-19 restrictions and maintains an office at the UBC School of Social Work, Faculty of Arts in Vancouver.

## Additional Funding

Activity	Date	Amount
Institute Funding from UBC Okanagan Vice Principal, Research and Innovation(VRPI) Office	2020/2021	\$50,000
Institute Funding from UBC Vancouver Faculty of Arts	2020/2021	\$25,000
Delta Community Living Society	2020/2021	\$ 2,000

## Community Engagements & Participation

### Representation on Community and Government Committees

- CIIC is a partner organization of the International Association for the Scientific Study of Intellectual and Developmental Disabilities Academy on Education, Teaching and Research.
- Hole. Reimagining Community Inclusion Employment Work Group – BC Ministry of Social Development and Poverty Reduction – [committee member] – March 2021 – Aug. 2021.
- Hole & Stainton. Canadian Leads and Founding Members, Citizen Network. International Network supporting Citizenship and Inclusion based in the UK.
- Stainton. Co-Chair, Canadian Association for Community Living Task Force on Medical Assistance in Dying.
- Stainton. Fellow and Member, International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD).
- Stainton. Member, Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA) Employment Curriculum Development Committee.
- Stainton. Member, IASSIDD Ethics Special Interest Research Group. Expert Advisory Group on Medical Assistance in Dying(MAiD). (International)
- Stainton. Member, Knowledge Core Committee, Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.(Canada)
- Stainton. Expert Advisory Group on MAiD (Medical Assistance in Dying) and Persons with a Mental Disorder, 2020.
- Stainton. Member, Accessibility Legislation & Covid-19 Advisory Committee, BC Ministry of Social Development and Poverty Reduction.
- Stainton. Member, Inclusion Canada Working Group on Income Security.
- Stainton. Member, Advisory Group on Business Case for IDD Medical Consultant. Advocate for Service Quality, BC Ministry of Social Development and Poverty Reduction.
- Stainton. Advisor, Vulnerable Persons Standard.
- Stainton. Member. Mental Health Research Canada’s Proposal Review Panel on a research initiative to mitigate COVID-19’s impact on mental health. Provincial Partners: Saskatchewan, Ontario, New Brunswick and British Columbia. Research calls to mitigate COVID-19’s impact on the mental health of children, youth and families in each jurisdiction.

## Consultations

- Hole. BC CEO Network – consultation on Home Sharing Research, Nov. 9, 2020.
- Stainton. Consultation with National Disability Organizations on response to Covid-19. March 2020.
- Stainton. Consultation with National Disability Organizations on MAiD/Bill C7 Ongoing.
- Stainton. Consultation with Inclusion BC, Covid-19/Vaccination Policy. (Successfully lobbied for all persons eligible for CLBC to be included in Phase 2 of Vaccination schedule).
- Stainton. Consultation with *In with Forward* on Curiko platform development.
- Stainton. External Ethics Consultant, Evaluation of Western Australia’s, Individualized Services Decision Making Possibilities Project. URBIS, Australia.
- Stainton. Expert Witness, RE: ‘MB’, Pacific Medical Law, Nov.5, 2020. (Report and consult).
- Stainton. Expert Witness, RE: ‘KL’, Pacific Medical Law, Nov.20, 2020. (Report and consult).
- Stainton. Expert Witness, RE: ‘KCS’, Pacific Medical Law, March, 21, 2021. (Report and consult).

## Editorships



- Rachele Hole, Consulting Editor, **The Journal of Policy and Practice in Intellectual Disability**
- Tim Stainton, Editorial Board, **Australian Social Work**
- Tim Stainton, Editorial Board **Journal on Social Inclusion**
- Tim Stainton, Co-Editor, **British Journal on Learning Disabilities, Special Issue on History**

## Hosted Community and UBC Events

- The Trampoline Effect Webinar. (November 9, 2020). Webinar hosted by the UBC Canadian Institute for Inclusion and Citizenship.
- Disrupting Misconceptions and Forging Pathways for Students with Disabilities. (February 23, 2021). Webinar co-hosted by the Canadian Institute for Inclusion and Citizenship and Inclusion BC.
- The Trampoline Effect Webinar – diving deeper. (Feb. 2021). Webinar hosted by the UBC Canadian Institute for Inclusion and Citizenship.

## Community, Government & University Partners

Collaboration is the key to the success of the Institute and we have a strong history of partnership and collaboration. Collaborators and partners have been instrumental to our successes and will continue to be anecessary foundation to our ongoing work. Collaborations and partnerships include UBC researchers, students, trainees, and community partners as well as national and international scholars, students, and partner organizations.

- Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.
- Autism Okanagan
- Autism Society of BC
- BC Centre for Employment Excellence
- BC Council of Administrators for Special Education
- BC Employment Network
- BC People First
- Burnaby Association for Community Inclusion
- Canucks Autism Network
- Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA), UBC
- Chilliwack Society for Community Living
- Citizen Network
- Community Living BC
- Community Living Society
- Community Living Victoria
- Delta Community Living Society
- Department of Anthropology, University of British Columbia
- Department of Occupational Science & Occupational Therapy, UBC
- Faculty of Education, UBC
- Faculty of Health Science, Simon Fraser University
- Family Support Institute of British Columbia
- Inclusion BC
- Inclusion Canada
- Inclusion Langley Society
- Indigenous Sport and Physical Activity Council of BC
- International Association for the Scientific Study of Intellectual and Developmental Disabilities
- Ministry of Children and Family Development (BC)
- Ministry of Social Development and Poverty Reduction (BC)
- Okanagan Nation Alliance
- Ontario Ministry of Community and Social Services
- Pacific Autism Family Centre
- Pacific Autism Family Network
- PosAbilities
- School of Kinesiology, UBC
- School of Psychology & Special Education, UBC
- Simon Fraser University

- Social Development Research Corporation
- Special Olympics BC
- Spirit of the Game Society
- Sun Peaks Adaptive Ski Program
- Sunny Hill Health Centre
- Therapeutic Recreation, Douglas College
- UBC Studios
- Unity WISE Employment Solutions
- University of Calgary
- University of Kansas
- Vela Canada
- Victoria Native Friendship Centre

## Goals for 2021 – 2023

We are committed to research, learning, and knowledge exchange.

### Research

- Conduct high quality, impactful research in the area of intellectual and developmental disability informed by the priorities and identified needs of the community living sector (provincially, nationally, and internationally) that attends to issues of equity and diversity
- Support existing partnerships and facilitate new partnerships to advance knowledge and practice to improve the lives of children, youth and adults with I/DD and their families
- Build research infrastructure and capacity in Canada in the area of I/DD research

### Learning

- Provide leadership and partnership opportunities for forums, Institutes, conferences, and symposiums aimed at increasing dialogue and knowledge on critical issues to the community living sector (e.g., 2016/17 “Diversity Includes Workshop Series”; 2015 “Claiming Full Citizenship Conference”)
- Secure research (and other) funding to provide undergraduate, graduate, and postdoctoral training and research opportunities (e.g., work study positions, research assistantships, practicums, and participation in community learning events and Institutes)

### Knowledge Exchange

- Engage in innovative knowledge translation and knowledge mobilization activities that includes self-advocates (individuals with intellectual and developmental disabilities to ensure that is low barrier and accessible (e.g., plain language documents)

## Proposed Activities

- Organize a stream focused on transitioning youth and employment at the 2023 World Congress on Supported Employment (Vancouver, BC)
- Build research capacity among self advocate consultants: In partnership with Inclusion BC, organize and host a Self Advocate Leadership Institute at UBC Okanagan
- Apply for MITACS and work study funding to support undergraduate and graduate student trainees – one specifically focused on gender equity and employment for self advocates with Inclusion BC
- Recruit and support 1 – 2 additional postdoctoral fellows in the next year
- Bring in international speakers to deliver public keynote talks at the TYDE annual general meetings (2022; 2023)
- Secure funding to deliver an annual speakers' series on issues of relevance to the sector
- Present research findings at annual Inclusion BC Conference/Learning Event
- Increase user accessibility features of Institute's website
- Engage with identified Provincial Ministry representatives regarding knowledge mobilization opportunities
- Develop and distribute an online newsletter
- Develop a webinar series on current issues relevant to the sector (host 4 webinars/year)
- Develop skills and expertise in innovative Knowledge Translation / Knowledge Mobilization KT/KM mediums
- Utilize white board animation to aid in dissemination of research findings
- Publish research findings in peer reviewed journals ensuring open access
- Create plain language Knowledge Translation (KT) summaries
- Launch a new website as part of the UBCO VPRI Interdisciplinary Research Website Pilot

## Contact Information

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Follow us on Twitter @CIICUBC and Facebook at Centre for Inclusion and Citizenship