



THE UNIVERSITY OF BRITISH COLUMBIA

## Canadian Institute for Inclusion and Citizenship



COLTON STERLING-MOSES  
INDIGENOUS DISABILITY AWARENESS MONTH CELEBRATION

## ANNUAL REPORT 2019 - 2020

Building on ten years of success as a research centre, the Canadian Institute for Inclusion and Citizenship (CIIC) was established by the Vice Principal - Research and Innovation at the UBC Okanagan Campus in 2019.

The CIIC was launched with a celebratory Indigenous Disability Awareness Month event at UBCO recognizing the valuable contributions that Indigenous persons living with disabilities bring to our communities.

We are Canada's first university - based research institute with a dedicated focus on social policy and practice issues concerned with the full inclusion and citizenship of people with intellectual and developmental disabilities.

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# Executive Summary

The Canadian Institute for Inclusion and Citizenship is at the forefront of building Canada's capacity in the field of intellectual and developmental disabilities (I/DD) research. The CIIC operates across both the UBC Okanagan and the UBC Vancouver campuses.

The goals of the Canadian Institute for Inclusion and Citizenship are closely aligned with the *UBC Strategic Plan: Shaping UBC's New Century*. The UBC Strategic Plan Vision is: "Inspiring people, ideas and actions for a better world." The Canadian Institute for Inclusion and Citizenship envisions a society that acts to achieve lives of quality for all citizens. Importantly, the work of the Institute specifically focuses on a population of people who historically experienced and continue to experience marginalization (e.g., institutionalization, segregation, social exclusion, stigmatization, to name a few). As such, through research, learning, and knowledge exchange, the Institute will continue to inform social change by promoting practices and cultures of inclusion. We will do this by keeping central the knowledge-users of this work: self advocates, family members, community (e.g., service providers), policy makers, government, and the private sector. As our mission states, we do this to "secure justice, equality, and well-being of all citizens" believing that inclusive and diverse communities and societies benefit all people.

Furthermore, the UBC Strategic Plan's Purpose commits to pursuing excellence in research, learning and engagement to foster global citizenship and advance a sustainable and just society across British Columbia, Canada, and the world. In a similar way, the Institute works to advance the inclusion and full citizenship of individuals with I/DD and their families, and to engage in research that informs policy and practice that advances these goals provincially, nationally, and globally. Moreover, our core beliefs underscore these commitments. We believe in inclusion, citizenship, access, lifelong learning, leadership, and collaboration and partnerships.

*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.*

## Directors' Message

*Rachelle Hole and Tim Stainton*

When sitting down to write our message this year, it was hard not to jump to 2020 having found ourselves in the middle of the COVID 19 pandemic that has impacted our work and those we care about. But before reflecting on the many ways we've responded to COVID 19 in our lives and in our work, there are and were many things to celebrate and mark that occurred during the 2019/2020 year. You will see from the contents of this report that, despite COVID 19, we have had a busy and productive year with numerous new projects and initiatives.

2019 marked the ten-year anniversary of the UBC Centre for Inclusion and Citizenship. It represented a time to reflect on a decade of work and the many successes that were only possible because of meaningful

partnerships with academic colleagues and community partners. It was also a time to look forward, dream, and plan for a future ten years of work together. One key outcome was set: to become a research institute at UBC. And, in May 2019, with the support of the DVC and Principal at UBC Okanagan and the Vice Principal Research and Innovation at UBC Okanagan, the UBC Okanagan Senate approved our application to become a UBC Institute at both UBC campuses.

As part of this transition, we formalized our relationships with existing research affiliates and established new connections by establishing formal research leads from both campuses: Dr. Jennifer Baumbusch, Dr. Lise Olsen, Dr. Karen Ragoonaden, & Dr. Leyton Schnellert. These researchers, along with Tim and Rachelle, lead four research streams: Policy, Practice, and Ethics; Employment and Transitions; Health and Well-being of Individuals with intellectual and developmental disabilities (IDD) and their Families Across the Lifespan; and Inclusive Education (<https://cic.arts.ubc.ca/research-streams>). In addition, while committed to attending to issues of diversity in all our work with an explicit commitment to being inclusive of Indigenous perspectives, we aim to formalize a fifth research stream committed to meaningful engagement with Indigenous communities, families, and people with IDD.

To celebrate this decade of work and partnerships and to celebrate the launch of the Institute, we gathered at UBC Okanagan in November to recognize Indigenous Disability Awareness Month in partnership with the BC Aboriginal Network on Disability Society, the Okanagan Nation Alliance, the UBC O Aboriginal Programs and Services, and the UBC Okanagan Disability Resource Centre. We also invited colleagues from across Canada to join us for discussions about establishing a national network of researchers and community partners with a goal to promote a national IDD research agenda that advances inclusion and equity for all. And, while there are many more activities and projects to celebrate, which this report highlights, we would be remiss not to reflect on the impact of COVID 19 on our lives and our work.

COVID 19 has exposed the precarity (vulnerability) of persons with intellectual and developmental disabilities and “has uncovered systems that lack policies and practices to be responsive to the needs of people with disabilities” and their families (Hole & Stainton, 2020). We want to recognize the great work of the self advocate organizations like the Self Advocate Leadership Network and our community partners who have worked to respond to the COVID 19 crisis. While our other research projects continue, researchers of the institute are involved in five COVID 19 related research projects. For example, Tim and Jennifer Baumbusch co-lead the Canadian implementation of an international survey on the impact of COVID 19 on individuals with intellectual disabilities and their families.

While COVID 19 has made life challenging for our students, we were happy to be able to provide a range of research and learning opportunities for many of them as well as opportunities to present at virtual conferences. Finally, while our connections are all virtual now, we appreciate the continued partnerships with our community partners and your contribution to the continued work of the Institute. And, of course, we want to thank Cindy Chapman, the Institute coordinator, who helps keep us on track.



## Message from the Provincial Advisory Board Chairperson

*Dan Collins, Executive Director, Inclusion Langley Society*

One of the most important messages communicated throughout most of 2020 has the notion that, “we are all in this together”. We can overcome the challenges that COVID-19 has presented if we look out for each other. This realization that community works when we all work together is not a new one for those of us who have been voices for inclusion. We strengthen our communities when we provide opportunities for everyone’s voices to be heard.

This sharing of perspectives and ideas is truly reflected in the work of the Institute. Its continued success is in part a result of the collaboration that occurs between academic colleagues and community partners. Over the years, we have used the term research with relevance to demonstrate how the intersection between academic research and the lived experience of individuals with intellectual disabilities and their family, friends and allies can inform policy and practice. This is especially true when we have opportunities to organize and allow for the transfer and exchange of knowledge. While in these times our exchanges may be virtual, we look forward to the future when we can once again be in each other’s company. The growing number of formalized research leads is a very exciting and hopeful development for the Institute. There is a renewed sense of optimism in this growth.

Achieving Institute status last year was a significant milestone for those of us who have been privileged to be members of the advisory board. The diversity of membership on the advisory board is a unique feature of the Institute and one that we hope brings value to the research that is occurring. Sincere thanks to each member for your continued belief in this collaboration. Lastly, we would echo Tim and Rachelle’s acknowledgement of Cindy Chapman and extend our appreciation to her for keeping us all connected.



NATIONAL RESEARCH NETWORK INITIATIVE MEETING, UBCO

# Acknowledgements



## Remembering Jerry Laidlaw

*Shared with permission from CLBC*

On November 6, 2019, we lost a dear friend, colleague and disability advocate, Jerry Laidlaw.

Jerry's leadership was far reaching and influenced the self advocacy and community living field in ways that have strengthened community for all of us. May we continue to learn from Jerry's story and keep asking questions about what is right and true, and worth fighting for. The following quote was taken from a series of presentations Jerry gave throughout his career:

"My name is Jerry Laidlaw. I'm a self advocate from Mission. Inclusion means to be part of society like everybody else, no matter your diverse abilities. It means having the same rights as everybody else.

I am passionate about helping others to use their voice. I think people who have been labelled just want to be seen and heard for who they are. Remember: ask the person what they want, not just what their family wants. All of us are able in some diverse way.

For me, it takes time to get to know someone. It's important to really trust the people in your life and stay close to the people who love you. It's important not to blame yourself and to always do your best. Often you meet people when you aren't expecting it. If you are looking for more people in your life, the best thing to do is go out there and do the things that make you happy. You never know who you might meet and where life will take you."



## Dr. Rachelle Hole awarded 2019 Researcher of the Year!

Each year, UBC Okanagan recognizes the outstanding achievements researchers who have made significant contributions to research and/or creative scholarly activity at UBC Okanagan.

This year's recipients epitomize excellence and are leaders in their respective fields and disciplines, working across traditional boundaries to help make the world a better place.

With a career spanning over 20 years working with individuals with physical and developmental disabilities, associate professor Rachelle Hole has focused her research on the socio-cultural practices that promote inclusion and equity. Learn a little bit more about Dr. Hole and her work at

<https://www.facebook.com/watch/?v=2375560592462497>

## 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 2019 - 2020, the CIIC undertook projects with a collective budget of \$3,732,108. New projects generated \$1,266,784 in new funding this reporting period and continued work on projects previously funded was in the amount of \$2,465,324. Researchers in **bold text** are CIIC Co-Directors, Research Leads and Co-Leads.

Funding Body	Title	Grant / Contract Total Amount	Funding Period	Principal Investigator	Co-Investigators	Collaborators & Partner Organizations (Knowledge Users and Policy Makers)
Michael Smith Foundation for Health Research	Implementing Physical Activity Programs in Communities for Children with Neurodisabilities	\$500,000	Sept 2019 – Aug 2022	<b>L. Olsen</b>	<b>Research Leads:</b> W. Mc Kellin JP Collet. M. Gititmoghaddam S. Glegg, T. Nault.  <b>Co – Is:</b>  <b>R. Hole</b> A. Miller W. McKee D. Whitehurst Jean Tatarenko S. Moore S. McGinley G. Faulkner R. Weber H. Banack J. Zwicker	<ul style="list-style-type: none"> <li>Indigenous Sport and Physical Activity Council of BC</li> <li>Special Olympics BC</li> <li>Spirit of the Game Society</li> <li>Sun Peaks Adaptive Ski Program</li> <li>Victoria Native Friendship Centre</li> </ul>
Social Sciences and Humanities Research Council	Assessing feasibility and effectiveness of an online parent resource to support safe and active sport and recreation for children with autism spectrum disorders	\$120,440	2019 - 2022	<b>L. Olsen</b>	A. McManus <b>R. Hole</b> G. Iarocci M. Brussoni	<ul style="list-style-type: none"> <li>Autism Okanagan</li> <li>Canucks Autism Network</li> </ul>

<b>Funding Body</b>	<b>Title</b>	<b>Grant / Contract Total Amount</b>	<b>Funding Period</b>	<b>Principal Investigator</b>	<b>Co-Investigators</b>	<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>
UBC Community-University Engagement Support Fund	Disrupting Misconceptions and Forging Pathways for Students with Developmental Disabilities	\$40,000	Jan 2020 – June 2021	<b>R. Hole</b> <b>L. Schnellert</b>		<ul style="list-style-type: none"> <li>• Inclusion BC</li> </ul>
Michael Smith Foundation for Health Research.	Literature and Jurisdictional Review on Respite Services with Knowledge Synthesis and Policy Options	\$161,261	2019	<b>T. Stainton</b> <b>R. Hole</b>	<b>J. Baumbusch</b> R. Young	
BC Ministry of Children and Family Development	Literature and Jurisdictional Review on Inclusive Child Care in the context of Universal Child Care with Knowledge Synthesis and Recommendations	\$12,000.	2019	<b>R. Hole</b> <b>T. Stainton</b>	<b>J. Baumbusch</b>	
VP Research & Innovation, UBC. Research Cluster Grant	Wingspan Dis/ability Arts, Culture, & Public Pedagogy	\$262,000	2019 - 2020	L. Roman	<b>T. Stainton</b> <b>L. Schnellert</b> (Cluster members)	
Mitacs Vela Canada	Vela Canada; Building Social Capital-Intern Fellowship	\$65,000	2019 - 2020	<b>T. Stainton</b>	<b>R. Hole</b>	<ul style="list-style-type: none"> <li>• Community Living British Columbia</li> <li>• Vela Canada</li> </ul>
Vancouver Foundation	Sexual Health Knowledge: A Participatory Theatre Research Project	\$145,000	2016 – June 2020	<b>R. Hole &amp; R. Chilton</b> (Community co-lead; Community Living Society)	<b>L. Schnellert</b> (Theatre Lead/Co-PI) <b>T. Stainton</b>	<ul style="list-style-type: none"> <li>• Anvil Centre</li> <li>• B. Gold</li> <li>• City of New Westminster</li> <li>• Community Living Society</li> <li>• Massey Theatre</li> </ul>



Funding Body	Title	Grant / Contract Total Amount	Funding Period	Principal Investigator	Co-Investigators	Collaborators & Partner Organizations (Knowledge Users and Policy Makers)
CIHR / SSHRC Partnership Grant  Awarded April 1, 2018	Transitioning Youth with Disabilities and Employment: The TYDE Project	\$2,320,324 (Includes partner cash and in-kind contributions)  CIHR/SSHRC funding \$1,331,650	2018 - 2023	<b>R. Hole</b>	S. Barnes J. Bottorff C. Crawford J. Domene <b>L. Schnellert</b> <b>T. Stainton</b> R. Williamson A. Wise R. Young	<ul style="list-style-type: none"> <li>• BC Aboriginal Network on Disability Society</li> <li>• BC Centre for Employment Excellence</li> <li>• BC Council of Administrators of Inclusive Support</li> <li>• BC Employment Network</li> <li>• BC Ministry of Children &amp; Family Development</li> <li>• BC People First</li> <li>• Community Living British Columbia</li> <li>• Family Support Institute of BC</li> <li>• Inclusion BC</li> <li>• Inclusion Canada</li> <li>• Simon Fraser University</li> <li>• UBC (Canadian Institute for Inclusion and Citizenship)</li> <li>• University of Calgary</li> </ul>

Funding Body	Title	Grant / Contract Total Amount	Funding Period	Principal Investigator	Co-Investigators	Collaborators & Partner Organizations (Knowledge Users and Policy Makers)
Ministry of Social Development and Poverty Reduction (MSDPR)	IMPACT: Youth with Disabilities Employment Project	\$106,083	Jan 2020 – Dec 2022	R. Hole	C. Reid T. Stainton	<ul style="list-style-type: none"> <li>• Burnaby Association for Community inclusion</li> <li>• Chilliwack Society for Community Living</li> <li>• Community Living Victoria</li> <li>• Delta Community Living Society</li> <li>• Inclusion Langley Society</li> <li>• Possibilities</li> <li>• Richmond Society for Community Living</li> <li>• Unity WISE Employment Solutions</li> <li>•</li> </ul>

## Student & Post Doctoral Supervision



TIM STAINTON & RAE MORRIS  
IASSIDD WORLD CONGRESS, GLASGOW SCOTLAND

The CIIC actively engages UBC students in the work of the Institute. The Institute's physical presence at both the Okanagan and Vancouver campuses has increased our ability to attract students and resulted in us having access to a large pool of graduate students with training in the latest research methods. We have extensive experience in quantitative, qualitative, and community-based participatory research methods.

In addition to their important contributions to the work of the CIIC, providing mentorship to undergraduate and graduate students

in the area of intellectual and developmental disabilities provides important recruitment and training for future careers in the community living sector in areas such as policy, practice, and research.

### 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 identifying/learn from emerging practice within BC and Canada.

### MSW Practicum Student

- Robin Metcalfe, UBCO

## Additional Student Supervision

Student Name	Program Type	Topic	Supervisor	Committee Members
Michelle Hewitt	IGS PhD	Long term care and residential options for younger adults with disabilities	<b>R. Hole</b>	<b>T. Stainton</b> C. Reid
Crystal Shannon	IGS PhD Nursing	Recreation for children and youth with ASD and their families in rural and remote communities	<b>L. Olsen</b>	<b>R. Hole</b> K. Rush
Mary Kjorven	IGS PhD Nursing	A post-structural autoethnography on the dual roles of nursing expert and a family member	K. Rush	<b>R. Hole</b> C. Reid <b>J. Baumbusch</b>
Sevinj Askerova <sup>c</sup>	PhD – Social Work	Critical Disability Studies – intellectual disabilities and reproductive technologies	<b>T. Stainton</b>	<b>R. Hole,</b> L. Nimmon
Shelly Moore	CFI PhD	Inclusive Education	<b>L. Schnellert</b>	
Kimberley MacNeil	Special Education PhD		<b>L. Schnellert</b>	
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)	<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>	
Pat Feindel	PhD, Simon Fraser University	Memory and Visibility: Speaking Through the Woodlands Memorial Garden		<b>T. Stainton</b>
Paige Reeves	PhD, University of Alberta	On the Margins: People with Intellectual or Developmental Disability Negotiate Belonging within Ableist Community		<b>T. Stainton</b>
Crystal Shannon	MSN	Rural supports for families with Autism Spectrum Disorder	<b>L. Olsen</b>	<b>R. Hole</b> K. Rush

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

- Ji Lixin, Shandong University

## Publications, Reports, Presentations and Performances

April 2019 – March 2020. CIIC researchers are highlighted in **bold**; students are underlined.

### Publications

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

**Baumbusch, J.**, Mayer, S., & Sloan Yip, I. (2019). Alone in a crowd? Parents of children with rare diseases' experiences of navigating the healthcare system. *Journal of Genetic Counseling*, 28(1), 80-90. doi.org/10.1007/s10897-018-0294-9

**Baumbusch, J.**, Moody, E., **Hole, R.**, Jokinen, N., & **Stainton, T.** (2019). Using healthcare services in the community: perspectives of aging adults with intellectual disabilities and family members. *Journal of Intellectual Disability Policy and Practice*, 16(1), 4-12.

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)

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.

**Hole, R.** <sup>SR/PI</sup>, Barnes, S., **Schnellert, L.**, Ngieng, N., **Stainton, T.**, Forby, L., & Polushin, S. (2019). Transitioning youth with disabilities and employment: The TYDE project. *Journal of Intellectual Disability Research*, 63 (7), 876.

**Hole, R.** <sup>SR/PI</sup>, Cook, S., Botorff, J. & **Stainton, T.** (2019). Improving employment outcomes for individuals with IDD: Gender matters! *Journal of Intellectual Disability Research*, 63 (7), 876.

**Hole, R.** <sup>SR/PI</sup>, Wells, T., Ben-David, S., & Graham, J. (2019). The benefits of hiring individuals with Intellectual and Developmental Disabilities: Employers' perspectives. *Journal of Intellectual Disability Research*, 63 (7), 876

Jones, K.E., Ben-David, S. & **Hole, R.** <sup>SR</sup> (2019) Are individuals with intellectual and developmental disabilities included in research? A review of the literature, *Research and Practice in Intellectual and Developmental Disabilities*, DOI: [10.1080/23297018.2019.1627571](https://doi.org/10.1080/23297018.2019.1627571)

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)

Reinders, J., **Stainton, T.** and Parmenter, T. R. (2019), The Quiet Progress of the New Eugenics. Ending the Lives of Persons with Intellectual and Developmental Disabilities for Reasons of Presumed Poor Quality of Life. *Journal of Policy and Practice in Intellectual Disabilities*, 16: 99-112. doi:10.1111/jppi.



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.

**Schnellert, L. & Hole, R.** (2019, August). *Romance, relationships, and rights: Theatre for social change*. ISBN: 978-1-988804-21-7, Kelowna, British Columbia: Institute for Community Engaged Research Press.

**Schnellert, L., Nelson, J., & Hole, R.** (2019, July). *Romance, relationships, and rights: A community creation*. ISBN: 978-1-988804-22-4, Kelowna. British Columbia: Institute for Community Engaged Research Press.

Downloaded August 3, 2019 from

[https://www.academia.edu/39790848/Romance Relationships and Rights A Community Creation](https://www.academia.edu/39790848/Romance_Relationships_and_Rights_A_Community_Creation).

**Schnellert, L.,** Richardsom, P., Roberts, E., McDonald, S., Rosal, A., Smith, J., MacHardy, C., Rader, M., & Fisque, J. & Hole, R<sup>SR</sup>. (2019). Enacting equity in higher education through critical disability studies: A critical community self study. *Disability Studies Quarterly*, 39 (2). <http://dsq-sds.org/article/view/6150/5252>

**Schnellert, L.,** Richardson, P., Roberts, E., Smith, J., MacHardy, C., Rader, M., MacDonald, S., Frisque, J., & **Hole, R.** (2019). Enacting equity in higher education through critical disability studies: A critical community self-study. *Disability Studies Quarterly*, 39(2). 32 pages.

**Stainton T., Morris, R.,** Perry L. and Bahadshah, Z. (2019) The Impact of a Community Microboard Program on Social Capital of Persons with Intellectual and Developmental Disabilities. *Journal of Intellectual Disability Research*, 63 (7), 850.

**Stainton, T.** (2019). Disability, vulnerability and assisted death: commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins. *BMC Med Ethics* **20**, 1-6. <https://doi.org/10.1186/s12910-019-0426-2>.

**Stainton, Tim** (2019) Achieving Citizenship and Inclusion. *Community Living* July 29, 2019/in 32.4.

Young, R., **Stainton, T.,** Marshall S. & Chi, E. (2019). Transition-to-adulthood: Prospective content in joint parent-youth conversations for young people with intellectual or developmental disabilities. *Journal of Intellectual Disability Research*, 63 (7).

## Commissioned Reports

**Hole, R.<sup>Co-PI</sup>, Stainton, T.<sup>Co-PI</sup>, , Baumbusch, J., Lawrason, S., & Sterling-Bur, S.** (Oct. 2019). *Inclusive Child Care in Universal Child Care Settings: A review of the literature*. The UBC Canadian Institute for Inclusion and Citizenship. Commissioned & funded research report by the BC Ministry of Children and Family Development to inform the new Children and Youth with Special Needs Provincial Framework.

**Hole, R.<sup>Co-PI</sup>, Stainton, T.<sup>Co-PI</sup>, Lawrason, S., Metcalfe, R., Sterling-Bur, S.** Sterling-Collins, R. Young, R. & **Baumbusch, J.** (Dec. 2019). *Comprehensive Literature Review: Respite Services and Supports* (CIIC 2019); Commissioned research report by the BC Ministry of Children and Family Development.

**Stainton, T.** <sup>Co-PI</sup>, **Hole, R.** <sup>Co-PI</sup>, **Baumbusch, J.**, Sterling-Bur, S., & Lawrason, S. (Oct. 2019). *Inclusive Child Care in Universal Child Care Settings: An environmental scan*. The UBC Canadian Institute for Inclusion and Citizenship. Commissioned research report by the BC Ministry of Children and Family Development

**Stainton, T.** <sup>Co-PI</sup>, **Hole, R.** <sup>Co-PI</sup>, Sterling-Bur, S., Lawrason, S., Metcalf, R., Sterling-Collins, R. Young, R. & **Baumbusch, J.** (Dec. 2019). *Environmental Scan: Respite Services – Canada* (CIIC 2019). Commissioned & funded research report by the BC Ministry of Children and Family Development to inform the new Children and Youth with Special Needs Provincial Framework.

**Stainton, T.** <sup>Co-PI</sup>, **Hole, R.** <sup>Co-PI</sup>, Sterling-Bur, S., Lawrason, S., Metcalf, R., Sterling-Collins, R. Young, R. & **Baumbusch, J.** (Dec. 2019). *Review of Respite Supports and Services: Knowledge Synthesis and Policy Options Paper* (CIIC 2019). Commissioned & funded research report by the BC Ministry of Children and Family Development to inform the new Children and Youth with Special Needs Provincial Framework.

Expert Advisory Group on Maid. (2020). *Canada at a Crossroads: Recommendations on Medical Assistance in Dying and Persons with a Mental Disorder – An Evidence-based Critique of the Halifax Group IRPP Report*. Toronto (ON): EAG.doi:10.13140/RG.2.2.36236.87687 or 10.13140/RG.2.2.36236.87687/1

## Publications Submitted

Breau, G.M., **Baumbusch, J.**, Thorne, S., Hislop, T.G., & Kazanjian, A. (early view, 2019). Primary care providers' attitudes towards individuals with intellectual disabilities: associations with experience and demographics. *Journal of Intellectual Disabilities*.

**Olsen, L.**, McFee, E., Shannon, C., **Hole, R.**, & Janke, R. (Resubmitted Feb 2020). Scoping review: Safe active recreation for children with ASD. *Journal of Developmental and Behavioral Pediatrics*.

Shannon, C.A., **Olsen, L.L.**, Rush, K., **Hole, R.** "There's nothing here": Perspectives from rural parents promoting safe active recreation of children living with autism spectrum disorders. Submitted Feb, 2020 to Research in Developmental Disabilities. (*currently under review*).

## Conference and Invited Presentations

B. Maes, H. Goll, **T. Stainton**, R. Brown & M. Nieuwenhuijse. (Aug. 2019) Roundtable: *The New Eugenics – Can Persons with Intellectual and Multiple Disabilities be happy?* World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.

**Hole, R.** (April 18, 2019). The Centre for Inclusion and Citizenship: *A Successful Cross-Campus Institute*. Presentation to the UBC Board of Governors at UBC Vancouver, BC.

**Hole, R.** (April 27, 2019). Keynote: *Employment Matters! Youth Matters! AND Gender Matters! What can parents do?* Richmond Transition Fair. Richmond, BC.

**Hole, R.** (June 18, 2019). *Transitioning Youth with Disabilities and Employment Project – Intervening to change employment outcomes for youth*. Focus Disability Network, Abbotsford, BC.

**Hole, R.** (June, 2019). *The Transitioning Youth with Disabilities and Employment Project: TYDE*. The Canadian Association of Supported Employment, Montreal, QC.

**Hole, R.** (June 21, 2019). Keynote: *Engaging Community Partners in Research: Collaboration, Ethics, and Knowledge Translation*. REB West, UBC Okanagan, Kelowna, BC.

**Hole, R.** (October 17, 2019) Keynote: *Promoting Keys to Citizenship*. 2019 Self Advocacy Conference. Richmond, BC.

**Hole, R.**, Barnes, S., **Schnellert, L.**, & Ngieng, N. (June 25, 2019). *Transitioning Youth with Disabilities and Employment: Developing a Low Barrier, Accessible Online Interactive Intervention*. The American Association on Intellectual and Developmental Disabilities, Minneapolis, Minn.

**Hole, R.**, Barnes, S., **Schnellert, L.**, Ngieng, N., & **Stainton, T.** (Aug. 7, 2019). *Transitioning Youth with Disabilities and Employment: Collaboratively Developing an Online Interactive Intervention Tool*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.

**Hole, R.**, Barnes, S., **Schnellert, L.**, Ngieng, N., **Stainton, T.**, Forby, L., & Polushin, S. (2019, Aug). *Transitioning youth with disabilities and employment: The TYDE project*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.

**Hole, R.**, Cook, S., Bottorff, J., & **Stainton, T.** (August 7, 2019). *Improving employment outcomes for individuals with IDD: Gender Matters!* World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.



RACHELLE HOLE

**Hole, R., Wells, T.,** Ben-David, S., & Graham, J. (August 8, 2019). *The benefits of hiring individuals with intellectual and developmental disabilities: Employers' perspectives of the Business Case*. The International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland.

**Hole, R., Wells, T.,** Ben-David, S., & Graham, J. (June 25 2019). *The Benefits to Hiring Individuals with Intellectual and Developmental Disabilities: The business case*. The American Association on Intellectual and Developmental Disabilities. Minneapolis, Minn.

**Hole, R.<sup>PI</sup>, & Schnellert, L.** (Feb. 12, 2020). *Research on stage: A knowledge mobilization workshop*. Institute for Community Engaged Research. Lake Country, BC

**Morris R., & Stainton, T.** (Aug. 2019). *Bridging the Gaps Between Research and Community: A Discussion of Theory*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland. (poster)

**Morris, R., Borje, C., & Stainton, T.** (October 25-29, 2019). "This model has really turned her life around": *Social Capital and Quality of Life Outcomes among Persons with Intellectual and Developmental Disabilities Involved in Microboards*. 25<sup>th</sup> Qualitative Health Research Conference. Vancouver, BC.

**Morris, R., Borje, C. & Stainton, T.** (May 2019). *How Do Microboards Help to Build and Sustain Social Capital, Self Determination and Improve Quality of Life*. Inclusion BC Conference, Victoria, BC.

**Olsen, L. L., Hole, R., Thompson, D., Shannon, C., & McFee, E.** (2019, Aug). *Exploring parent experiences of child elopement behaviour in the context of active and safe recreation for families with children living with autism spectrum disorders*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland.

**Schnellert, L.** (2019, May). *Working together to support all learners*. Keynote presented at the annual conference of Inclusion BC. Victoria, BC.

**Schnellert, L., Kozak, D., & Moore, S.** (2019, April). *Collaborative inquiry for inclusion: Professional development that positions teachers as inquirers and possibilizers*. Keynote presented at the annual conference of BCCASE. Vancouver, BC.

**Shannon C.A., Olsen, L.L, Hole, R., & Rush, K.** (2019, Aug). *Parent experiences promoting safe and active recreation for children living with autism spectrum disorders in rural settings*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland. (poster).

**Shannon C., Olsen, L., Hole, R., & Rush, K.** (Dec 2019) *"There's nothing here": perspectives from rural parents promoting safe active recreation for children living with autism spectrum disorders*. Invited to include poster presentation as part of the Kids Brain Health Network section of the Children's Health Care Canada Poster Fair, December 9, 2019. Ottawa, ON. (Poster).

**Shannon, C.A., Olsen, L.L., Hole, R., & Rush, K.** (2019 August). *Parent experiences promoting active and safe recreation for children living with autism spectrum disorders in rural settings*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland, UK.



**Stainton T., Morris, R., Perry L. & Bahadshah, Z.** (Aug. 2019) The Impact of a Community Microboard Program on Social Capital of Persons with Intellectual and Developmental Disabilities. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland. (poster)

**Stainton, T.** (Feb. 25, 2020). *Disability Vulnerability and MAiD*. 90<sup>th</sup> Anniversary Symposium on Social Justice and an Ethic of Care. School of Social Work, UBC Vancouver.

**Stainton, T., Hole, R.<sup>co-PI</sup>, & Crawford, C.** (August 2019). *Ready Willing and Able: Employers' experiences of hiring employees with intellectual disabilities or Autism*. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.

**Stainton, T., A. Schippers, S. Magaña<sup>4</sup>, T. Parmenter and I. Brown** (Aug. 2019) Roundtable: *The New Eugenics - What Do Families Say About Ethics and Quality of Life?* World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland.

**Stainton, T.** (Jan 18, 2020). *The Multiple Intersections of Disability and Art*. Wingspan Disability Arts Project Symposium, Green College, UBC Vancouver.

**Stainton, T.** (May 31 – June 1, 2019) *Disability, Vulnerability and MAiD*. 3rd Annual National Conference on Medical Assistance in Dying (MAiD). Vancouver, BC.

**Stainton, T.** (May 28-29, 2019) *Disability, Vulnerability and MAiD*. At the Edge of Medical Assistance in Dying Peter Wall Symposium. UBC Vancouver.

**Stainton, T., Reinders H. & Parmenter, T.** (August 2019). *The New Eugenics – Concerns, Arguments and Questions*. IASSIDD Academy Workshop, Glasgow, Scotland.

**Stainton, T.,** (Jan. 8, 2020) Lecture on Disability, MA in Genetic Counselling, UBC.

Young, R., **Stainton, T.,** Marshall S. & Chi, E. (Aug, 2019). Transition-to-adulthood: Prospective content in joint parent-youth conversations for young people with intellectual or developmental disabilities. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. Glasgow, Scotland. (poster)

## Performances

**Schnellert, L., Nelson, J., Hole, R., & 15 Self-Advocate Co-Creators.** (2019, May). *Romance, relationships, and rights: A community creation*. Three performances (May 15, 16, 17) at the Anvil Theatre: New Westminster, British Columbia.

**Schnellert, L., Nelson, J., Hole, R., & 15 Self-Advocate Co-Creators.** (2019, May). *Romance, relationships, and rights: A community creation*. Performance (May 25) at the Inclusion BC annual conference. The Empress Hotel Main Ballroom: Victoria, British Columbia.





JUSTIN VAN CLEEF & LARISSA GUNKEL  
ROMANCE, RELATIONSHIPS & RIGHTS

Romance, Relationships & Rights, A  
Community Creation. May 2019 Performance

<https://youtu.be/M84Qpyn1vLU>

Romance, Relationships and Rights: Theatre for  
Social Change. May 2019

<https://youtu.be/CyELdpqeOyw>

## Media

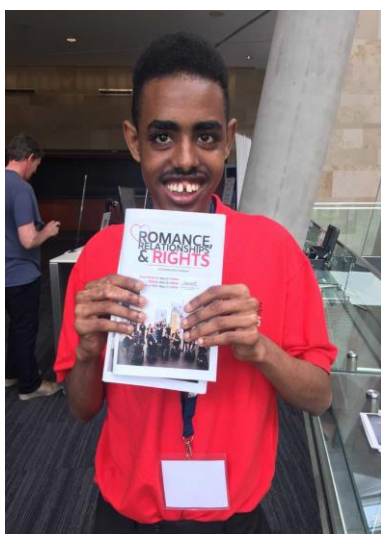
CBC Story – Saturday, May 18, 2019. We're just like everybody else: new play tackles misconceptions about disabilities love and sex. Funded by the Vancouver Foundation Dr. Rachelle Hole is the PI on this project.

<https://www.cbc.ca/news/canada/british-columbia/we-re-just-like-everybody-else-new-play-tackles-misconceptions-about-disabilities-love-and-sex-1.5139592>

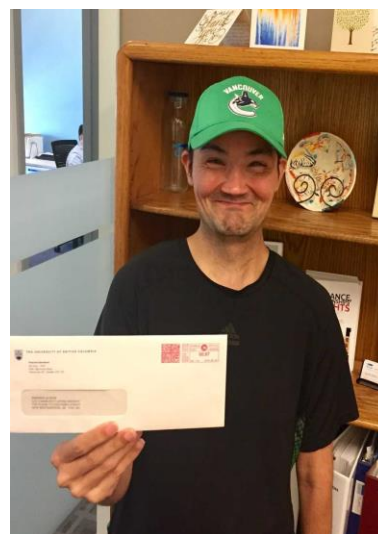
The Record (New Westminster, May 8, 2019) The right to romance: New play tackles misconceptions and stereotypes. Funded by the Vancouver Foundation. Dr. Rachelle Hole PI

[https://www.newwestrecord.ca/entertainment/the-right-to-romance-new-play-tackles-misconceptions-and-stereotypes-1.23815494?utm\\_source=dlvr.it&utm\\_medium=twitter](https://www.newwestrecord.ca/entertainment/the-right-to-romance-new-play-tackles-misconceptions-and-stereotypes-1.23815494?utm_source=dlvr.it&utm_medium=twitter)

AMI (Accessible Media Inc.) – Audio Toronto – *Romance, Relationships, and Rights*. Funded by the Vancouver Foundation – Dr. Leyton Schnellert was interviewed and Dr. Rachelle Hole is the PI on the project.



MERHAWEI NEGASH



KURTIS JOHNSON

# 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, UBC Vancouver**

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

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**

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 3 years.

## Research Project Descriptions & Selected Highlights

### Sex, Lies and Citizenship / Romance, Relationships & Rights

Funded by the Vancouver Foundation in partnership with the Community Living Society, Anvil Centre, Massey Theatre and supported by the UBC Department of Theatre and Film and Real-Talk.

Sex, Lies & Citizenship was 3-year community-based participatory theatre project focused on improving sexual health knowledge and positive sexuality among self advocates. Building on research gathered in an earlier Sexual Health Knowledge pilot project, Sex, Lies and Citizenship conducted an additional series of interviews with self advocates. Using what was learned in the research and in collaboration, self advocate co-creators and actors used community-based participatory methods to co-create and produce a participatory theatre project. Through facilitated activities, the Company created scenes, the dialogue within them, and Romance, Relationships, and Rights was born!

The performance confronted misconceptions about adults with intellectual disabilities and challenged audiences to think differently about how we value, respect and support self-advocates' rights to romance and intimate relationships.

Undergraduate students, graduate students and theatre professionals co-facilitated the development of the theatre piece and mentored self-advocate actors and technicians. UBC student and Assistant Stage Manager Catherine McLaren noted, "this invigorating collaborative experience has shown me how accessible and adaptable theatre can and should be."



ROMANCE, RELATIONSHIPS & RIGHTS ACTORS/CO-CREATORS

### **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 will create 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.

### **Microboards, Social Capital, Self Determination & Quality of Life**

Funded by Mitacs with Vela Canada and Community Living British Columbia.

Microboards are small groups of people who have agreed to collaborate with an individual with a disability to form a person-centered ‘board’. This project questioned if and how Microboards increase and individual’s social capital. The research team is presently working with UBC Studios on knowledge translation materials including an info-graphic and animated/whiteboard video.

### **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.

### **Assessing feasibility and effectiveness of an online parent resource to support safe and active sport and recreation for children with autism spectrum disorders.**

Funded by Social Sciences and Humanities Research Council.

Focus areas include child injury prevention, promotion of physical activity for children and families, and understanding the experiences of parents who have a child living with a chronic condition or disability. A main focus is on the needs of families who have a child living with Autism Spectrum Disorder (ASD). We are aiming to learn how families can be better supported to promote their children’s health through safe and active physical activities.

### **Review of Respite Supports and Services for Children and Youth with Special Needs**

Commissioned & funded research report by the Michael Smith Foundation for Health Research on behalf of the BC Ministry of Children and Family Development to inform the new Children and Youth with Special Needs Provincial Framework. The project completed a literature review, jurisdictional scan, knowledge synthesis paper and recommendations.



### **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.



TYDE PROJECT PARTNER CONSULTATION

### **Literature and Environmental Scan of Inclusive Child Care in the Context of Universal Child Care**

Commissioned & funded research report by the BC Ministry of Children and Family Development to inform the new Children and Youth with Special Needs Provincial Framework

### **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.

# Team Members

## Co-Directors

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

- Barry Isaacs, Director of Research, Evaluation and Education, Surrey Place
- Dr. Alison McManus, Professor, Health and Exercise Science, UBCO
- Dr. Alyssa Wise, Director, NYU Learning Analytics Research Network (NYU-LEARN)
- Dr. Ann Fudge Schormans, Associate Professor, School of Social Work, McMaster University
- Dr. Anton Miller, Sunny Hill Health Centre
- Dr. Cameron Crawford, School for Disability Studies, Ryerson University
- Dr. Colin Reid, Health and Exercise Sciences, UBCO
- Dr. David Whitehurst, Faculty of Health Science, Simon Fraser University
- Dr. Elizabeth Anderson, School of Nursing, UBCV
- 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. Ivan Brown, Adjunct Professor, Department of Applied Disability Studies, Brock University
- 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, UBCO
- Dr. Jose F. Domene, Werklund School of Education, University of Calgary,
- Dr. Kendra Thomson, Associate Professor, Department of Applied Disability Studies, Brock University
- Dr. Kirsty Johnston, Professor, Theatre Studies, Department of Theatre and Film, UBC
- 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 Lunskey, 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
- Ross Chilton, CEO, Community Living Society
- Steve McGinley, Faculty of Education, UBC
- Tara Nault, Indigenous Sport, Physical Activity & Recreation Council, BC

## Research Assistants and Staff

### Research Assistants/Students

- Catherine McLaren, Co-Director / Assistant Stage Manager, Romance, Relationships & Rights
- Celeste Borja, BSW, Microboards and Social Capital Project
- Haley Lor, Co-Director, Romance Relationships & Rights
- John Segui, BSW, Microboards and Social Capital Project
- Kimira Bhikum, Scenic Designer, Romance, Relationships and Rights
- Laura Mudde, PhD, IMPACT Project
- Leilani Forby, MA/PhD, TYDE Project
- Megan “Fosse” Fass, Stage Manager, Romance, Relationships & Rights
- Rachel Shaen, Lighting Designer, Romance, Relationships & Rights
- Rae Morris, PhD, Microboards and Social Capital Project
- Robin Metcalfe, MSW, TYDE Project, MSFHR Respite Project
- Sandra Polushin, PhD (Simon Fraser University), TYDE Project (UBC GAA)
- Sarah Lawrason, PhD – MCFD Inclusive Childcare Project; MSFHR Respite Project
- Sue Sterling-Bur, PhD – TYDE Project; MCFD Inclusive Childcare Project; MSFHR Respite Project, and Inclusion BC Project on Inclusive Education

### Research Staff

- Aidin Niavarani, Application Lead Developer, TYDE Project
- Emily Giroux, MSC, Research Coordinator, TYDE Project
- Linnea Ritland, BFA, Lead Video and Animation TYDE Project

## Work / Learn Students

- Celeste Borje, UBC Vancouver
- Emma Smith, UBC Okanagan
- Rebecca Stainton, UBC Okanagan

## Project Contractors

- Daphinie Situ, TYDE Project, Assistant Animator
- Heidi Damayo, TYDE Project, Voice Actor
- Jaclyn, TYDE Project, Background Designer
- Jed Weiss, TYDE Project, Voice Actor
- Jessica Ann Nelson, Romance, Relationships & Rights, Co-Producer / Co-Director
- Justin Murray, TYDE Project, Composer and Voice Actor
- Kim Nipp, TYDE Project, User Design and Animation Assistant
- Natalie Backerman, TYDE Project, Voice Actor
- Rachel Whitehead, TYDE Project, Storyboard Artist
- Rona Sterling-Collins, MSFHR Respite Project, Researcher
- Sammie Hatch, Romance, Relationships & Rights, Sound Designer
- Shona Struthers, TYDE Project Voice Actor
- Spencer Soares, TYDE Project, Voice Actor and Character Animator

## Staff

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



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## 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 and in volunteer roles as appropriate (e.g., as members of the Advisory Board).

- Aaron Pietras, Sex, Lies and Citizenship Project / Romance, Relationships & Rights
- Colton Sterling-Moses, TYDE Project
- Dale Froese, CIIC National Research Network Initiative
- David Johnston, TYDE Project
- Erin Boe, TYDE Project
- Joanne Gauthier, Plain Language Consultant, Social Capital Project
- Jose Figueroa, TYDE Project
- Kaitlin Smith, TYDE Project
- Kyle Youmans, TYDE Project
- Leanne Froese, CIIC National Research Network Initiative
- Michael McLellan, Plain Language Consultant, Social Capital Project
- Shameera Rosal, TYDE Project



SHAMEERA ROSAL & RACHELLE HOLE, TYDE PROJECT



# 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 2019 – 2020

- Dan Collins, Inclusion Langley Society, Chair
- Angela Clancy, Family Support Institute of BC
- Jack Styan, Community Living BC
- Janice Barr, Community Living Society
- Jason Gordon, BC Association for Child Development and Intervention
- Jerry Laidlaw, Self Advocate Consultant
- Joanne Gauthier, BC People First
- Karla Verschoor, Inclusion BC
- Kathleen Haggith, North Island College
- 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

Presently, 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. Both Dr. Hole's office and the board room are not accessible to individuals who use wheelchairs or other mobility devices. In addition, with the award of the recent TYDE partnership grant, additional work station space is needed for staff and research assistants (RAs) of the TYDE project in addition to existing and future RAs from other projects. Other potential uses of the space based on past practices is supervising UBC Okanagan School or Social Work practicum students and providing space for a School of Social Work sessional instructor. It would be beneficial to have a new space for the Institute at UBC Okanagan to increase the profile of the Institute (to have its own identity), to address increased capacity and infrastructure needs, and to ensure that the space is accessible to those with disabilities.

## UBC Vancouver

The CIIC Coordinator is presently housed in an office at the School of Social Work in Vancouver. Work space for student trainees and work study students is limited and has been provided on an as needed basis. Meeting rooms in the Jack Bell Building are used to host public learning and knowledge exchange events as well as meetings of the Provincial Advisory Board. At this time, we do not anticipate requiring any additional space at UBC Vancouver.

## Additional Funding

Activity	Date	Amount
CIIC National Strategic Research Planning Day, Supported by the UBCO DVC and Principal's Office	Nov. 21 – 22 2019	\$8,600
Indigenous Disability Awareness Month Event, Supported by the BC Aboriginal Network on Disability Society	Nov. 22, 2019	\$4,000
Institute Funding from UBC Okanagan Vice Principal, Research and Innovation (VRPI) Office	2019/2020	\$50,000
Institute Funding from UBC Vancouver Faculty of Arts	2019/2020	\$25,000



TYDE PROJECT VIDEO PRODUCTION

# 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. Member, BC Representative for Children and Youth Multidisciplinary Team Committee. Nov 2015 – Spring 2020.
- 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 MAiD.
- Stainton. Member, Knowledge Core Committee, Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.
- Stainton. Expert Advisory Group on MAiD (Medical Assistance in Dying) and Persons with a Mental Disorder, 2020

## Consultations

- Stainton. Academic Consultant. Review of Early Childhood Development Programs, Social Development Research Corporation on behalf of MCFD.
- Stainton. Consultation with National Disability Organizations on response to Covid-19. March 2020.
- Stainton. Expert Witness: RE: I A L et al v Y C et al, Supreme Court of British Columbia, Vancouver Registry No VLC S S 118637.
- Stainton. Invited Consultation with Canadian Federal Ministers of Justice, Health and, Workforce Development and Disability Inclusion on reform of MAiD legislation. Vancouver Jan. 16, 2020.
- Stainton. Ontario Ministry of Community and Social Services. Consultation on Service System reform. May 21, 2019.
- Stainton. Powell River Association for Community Living. Consultation with board on MAiD. Dec. 7, 2019.

## Editorships



- Rachelle 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, Editorial Board, **British Journal on Learning Disabilities**

## Hosted Community and UBC Events

- **Career Construction & Life Design: Self Determination and 21<sup>st</sup> Century Work-Life Skills**, Dr. Michael Weymeher, University of Kansas, April 8, 2019, UBC Robson Square, Vancouver.
- **Social Perspectives on Disability: Research, policy and practice**. A week – long intensive course delivered in partnership with Hebrew University of Jerusalem for UBC and HUJ students. July 2019, School of Social Work, UBC Vancouver.
- **New Eugenics Conference Stream** co-organized for the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Aug. 2019. Glasgow, Scotland.
- **CIIC National Research Network Meeting** to discuss the establishment of a National Research Network focused on Intellectual and Developmental Disabilities. 27 participants from across Canada. Funded by the UBC Okanagan Deputy Vice - Chancellor and Principal. November 21 & 22, 2019. UBC Okanagan.
- **CIIC Launch & Indigenous Disability Awareness Month Event**, a celebratory event recognizing the valuable contributions that Indigenous persons living with disabilities bring to our communities. Featuring Madeline Terbasket, Syilx, Ho-Chunk, Anishinaabe Performing Artist. Co-hosted in partnership with the BC Aboriginal Network on Disability Society, Okanagan Nation Alliance, UBCO Aboriginal Programs and Services, and UBCO Disability Resource Centre. November 22, 2019, UBC Okanagan.



## CIIC Launch & Indigenous Disability Awareness Month Event, November 2019, UBC Okanagan



AMBER CARENAS



NEIL BELANGER, BCANDS



COLTON STERLING-MOSES



GROUSE BARNES, WESTBANK FIRST NATION



## 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 a necessary 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.

- Anvil Centre
- Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.
- Autism Okanagan
- Autism Society of BC
- BC Aboriginal Network for Disability Society
- BC Centre for Employment Excellence
- BC Council of Administrators for Special Education
- BC Employment Network
- BC People First
- BC Representative for Children and Youth
- Burnaby Association for Community Inclusion
- Canadian Association for Community Living
- Canadian Federal Ministers of Justice, Health and, Workforce Development and Disability 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
- Department of Theatre and Film, UBC
- Faculty of Education, UBC
- Faculty of Health Science, Simon Fraser University
- Family Support Institute of British Columbia
- Hebrew University of Jerusalem
- Inclusion BC
- Inclusion BC Self Advocate Advisory Committee
- Inclusion Langley Society
- Indigenous Sport and Physical Activity Council of BC
- International Association for the Scientific Study of Intellectual and Developmental Disabilities
- Madeline Terbasket, Syilx, Ho-Chunk, Anishinaabe Performing Artist
- Massey Theatre
- Ministry of Children and Family Development (BC)
- Ministry of Social Development and Poverty Reduction (BC)
- North Island College
- Okanagan Nation Alliance
- Ontario Ministry of Community and Social Services
- Pacific Autism Family Centre
- Pacific Autism Family Network
- PosAbilities
- Powell River Association for Community Living
- Real Talk
- Richmond Society for Community Living
- School of Kinesiology, UBC
- School of Psychology & Special Education, UBC
- Self Advocate Net

- Self Advocates of Semiahmoo
- 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
- UBCO Aboriginal Programs and Services
- UBCO Disability Resource Centre
- Unity WISE Employment Solutions
- University of Calgary
- University of Kansas
- Vela Canada
- Victoria Native Friendship Centre

## Initiatives

### I Am Voting: Federal Election 2019

A multi-agency initiative with the goals of:

- ensuring that all people with disabilities can participate fully in election activities and vote;
- promoting priority attention for disability issues in the election;
- supporting people with disabilities in making informed voting decisions.



@IAmVotingFederalElection2019



I Am Voting Federal Election 2019



@IAmVoting2019



@IAmVoting2019

# Goals for 2020 – 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 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 and host international conference for TYDE CIHR/SSHRC project in 2023
- Apply for MITACS and work study funding to support undergraduate and graduate student trainees
- Recruit and support 1 – 2 postdoctoral fellows within the next three years
- Bring in international speakers to deliver public keynote talks at the TYDE annual general meetings (2019 – 2023)
- Build research capacity among self advocate consultants
- 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
- 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

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Learn more about the CIIC on our website at <https://cic.arts.ubc.ca>.  
 Follow us on Twitter @CIICUBC and Facebook at Centre for Inclusion and Citizenship