



THE UNIVERSITY OF BRITISH COLUMBIA

Canadian Institute for Inclusion and Citizenship

# ANNUAL REPORT

## 2021 – 2022



*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

## Message from the Provincial Advisory Board Chairperson

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

I can't overstate the importance of the Canadian Institute for Inclusion and Citizenship to community. At a time when we are experiencing unprecedented challenge and change in our lives, in our communities and in the systems and services so many rely on to live a good life, research is vital. No doubt many among us explore an issue or challenge and see obvious solutions. These obvious solutions may or may not be considered by those with the ability to enact change. This is where research plays a critical role in shaping our responses and informing the way forward. The capacity of the Institute to partner with community entities and translate findings into legitimate ways forward is the core of its purpose.

The Institute prides itself on its relationship with community, with self-advocates, with families, with community service providers and decision makers. It successfully partners with communities to explore new approaches to support and service, conduct literature and jurisdictional reviews to inform the path forward and evaluate the efficacy of a variety of approaches to service and support. Most importantly, the Institute broadly shares its learnings and knowledge. This unique opportunity to impact the future through evidenced based decision-making must be preserved.

Sincere thanks to the members of advisory board who continue to champion the importance of research and the inherent value in and relevance of research.

## Directors' Message

*Rachelle Hole & Tim Stainton*

Each year as we sit down to write our annual report, it provides an opportunity to reflect on all of our activities. Again, it has been a busy year with numerous continuing projects as well as new research projects with both longstanding community partners as well as new partnerships. But this year, as reflected in Dan's message, it's been a time to reflect on the role of the Institute: where we have been and where we hope to go in the future.

The UBC Strategic Plan's Vision is: "Inspiring people, ideas and actions for a better world." It further highlights three themes that are key opportunities for transformational change: inclusion, collaboration, and innovation. The collective work of the CIIC clearly aligns with this vision and demonstrates engagement with these three themes. The CIIC envisions a society that acts to achieve lives of quality for all citizens and inclusion, collaboration, and innovation are evident in our research, learning, and knowledge exchange.

The Institute is a unique entity at a university in that our origins began in community where community partners identified the need for an entity to conduct research to inform policy and practice in the community living sector. This legacy informs our work as it speaks to the importance of collaborations and partnerships provincially, nationally, and globally. Through our impact on policy and practice we

aim to advance the inclusion and full citizenship of self-advocates and their families, and their supporters. Self-advocates, family members, community stakeholders (e.g., service providers), policy makers, and government partners play key roles in our work. One example is the Transitioning Youth with Disabilities and Employment Project (see page 25). Moreover, this project is an example of our commitment to attend to issues of diversity. For example, one key priority of the TYDE Project is to ensure we are inclusive of Indigenous youth and families, and embedded in the design is a commitment to attend to other factors of diversity such as gender, ethnicity, geographic diversity, socioeconomic status, and more. Another example of inclusion and collaboration is Tim and Jennifer's work with The Royal Society of Canada on Covid-19 and intellectual disability where they contributed their ideas but also, in consultation with self-advocates, ensured a plain language version of the report was available.

Partnerships and collaborations are vital to the success and impact of the CIIC. These collaborations provide opportunities to mentor trainees (e.g., graduate students) and junior scholars across both campuses, and expose them to the incredible and important work of the sector. For example, the past two years we have had UBC students work with the Self Advocate Leadership Network. Students who have been involved gain valuable insights about inclusion including the importance of plain language. The role of self-advocates as mentors, advisory board members, co-presenters, co-researchers is highly valued, and we strive to do better with our practices of inclusion and creating information that is accessible and useful to all our stakeholders and partners.

While in our work we often respond to funding opportunities, we are committed to engaging in work with real impact. As such, we want to be responsive to community stakeholder needs and requests to the best of our ability.

So, this year we want to thank all of you who invest and partner with us in this important work. It makes our work so enjoyable and contributes to the impact of the CIIC. Finally, we want to thank our advisory board members (current and past) for their contributions and direction as we continue to grow as an institute. And, of course, we thank Cindy for her incredible stewardship of the CIIC.

## Acknowledgements

**Sincere thanks** to Angela Clancy, Executive Director of the Family Support Institute of BC who has stepped down from our Provincial Advisory Board. Angela is a long time contributor to our work and we have greatly appreciated the role she has played representing voices of families. While we will miss her presence on the advisory board we look forward to continued and future collaborations.

**Congratulations to Dr. Jennifer Baumbusch** who has been appointed the Canadian Institute of Health Research Sex & Gender Science Chair Dynamics of Caregiving in an Aging Society (2020 – 2024). Dr. Baumbusch 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. She has expertise in critical ethnography and practice-close research. Jennifer is committed to community-based research principles through active engagement of individuals, clinicians, service providers, and organizations.

**Congratulations to Dr. Rachelle Hole.** We are very pleased to share that Co-Director Dr. Rachelle Hole has been promoted to Full Professor within the Faculty of Health and Social Development, School of Social Work at UBC Okanagan. This is very well deserved recognition of her major scholarly contributions, many of which we have been privileged to share through the work of the CIIC.

## 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 2021 - 2022, the CIIC undertook projects with a collective budget of \$4,738,844. New projects generated \$1,037,843 in new funding this reporting period and continued work on projects previously funded was in the amount of \$3,701,001. Researchers in **bold text** are CIIC Co-Directors, Research Leads and Co-Leads.

<b>Title</b>	<b>Ableism and Employment Equity</b>		
<b>Funding Body</b>	<b>BC's Office of the Human Rights Commissioner</b>		
<b>Grant / Contract Total</b>	\$15,000	<b>Funding Period</b>	2021-2025
<b>Principal Investigator(s)</b>	Hole, R. Stainton, T.	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>			
<b>Title</b>	<b>Evidence to Inform Policy and Practice in the Community Living Sector</b>		
<b>Funding Body</b>	<b>Community Living British Columbia</b>		
<b>Grant / Contract Total</b>	\$300,000	<b>Funding Period</b>	2021-2025
<b>Principal Investigator(s)</b>	Hole, R. Stainton, T.	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Community Living BC		
<b>Title</b>	<b>From kindergarten to post-secondary: Exploring the educational journeys of students with disabilities</b>		
<b>Funding Body</b>	Social Sciences and Humanities Research Council		
<b>Grant / Contract Total</b>	\$298,969	<b>Funding Period</b>	2021 - 2024
<b>Principal Investigator(s)</b>	<b>Baumbusch, J.</b>	<b>Co-Investigator(s)</b>	<b>Hole, R., Poon, &amp; Cannon</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	North Vancouver School District; Inclusion BC; STEPS Forward; BC Ministry of Education; BC Ed Access		

<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>	<b>CIHR – COVID Mental Health and Addictions Operating Grant Competition</b>		
<b>Grant / Contract Total</b>	\$199,996	<b>Funding Period</b>	Sept 2020 – Aug 2021
<b>Principal Investigator(s)</b>	Lunsky (NPI) Thakur (PI) Lake (PI), Durbin (PI)	<b>Co-Investigator(s)</b>	Hamdani, Y(Co-I), Thomson, K. (Co-I), McMorris, C. (Co-I), Bobbette, N. (Co-I), <b>Hole, R. (Co-I),</b> [BC LEAD] Sockalingam (Co-I), Durbin, J. (Co-I), Hardy, J. (Co-I), Steel, L. (KU), Ries, H. (KU), Streisslberger (KU), Grier, L. (KU).
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>			
<b>Title</b>	<b>Remote Supports as a Service Delivery Option for Individuals Accessing Community Living Supports</b>		
<b>Funding Body</b>	Vancouver Foundation, Community Living British Columbia, Mitacs, Community Partners		
<b>Grant / Contract Total</b>	\$194,000	<b>Funding Period</b>	2021 – 2023
<b>Principal Investigator(s)</b>	Community Living Society <b>Hole, R.</b> (Academic Lead)	<b>Co-Investigator(s)</b>	
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	ASPIRE, Inclusion Langley; Spectrum Society for Community Living, Inclusion BC		
<b>Title</b>	<b>Understanding and mitigating the impact of COVID-19 on the mental health of parents and caregivers of children and youth with special needs in British Columbia.</b>		
<b>Funding Body</b>	Mental Health Research Canada (MSFHR & MCFD)		
<b>Grant / Contract Total</b>	\$50,000	<b>Funding Period</b>	2021 - 2022
<b>Principal Investigator(s)</b>	<b>Baumbusch, J. &amp; Clancy, A</b>	<b>Co-Investigator(s)</b>	<b>Hole, R., Lee, E., Jenkins, E., Olsen, L.</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Tracy Humphreys (BC Ed Access), Sacha Bailey (BC Centre for Ability) <b>Tim Stainton</b> (UBC CIIC), Jaime Wegner-Lohin (BC Rep for Children and Youth), Mary Stewart, Karla Verschoor (Inclusion BC)		

<b>Title</b>	<b>Understanding the Impact of COVID-19 on Children with Medical Complexity and Their Families</b>		
<b>Funding Body</b>	Canadian Institute for Health Research: Operating Grant		
<b>Grant / Contract Total</b>	149,874	<b>Funding Period</b>	2022
<b>Principal Investigator(s)</b>	Baumbusch, J., McGuire, M.	<b>Co-Investigator(s)</b>	Bailey, S., Lee, E.
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>			
<b>Title</b>	<b>The Transitioning Youth with Disabilities and Employment Project – “The TYDE Project” – Focus on Gender Equity: Why are jobs distributed so unequally across gender?</b>		
<b>Funding Body</b>	Mitacs		
<b>Grant / Contract Total</b>	\$30,000	<b>Funding Period</b>	2021
<b>Principal Investigator(s)</b>	Inclusion BC and R. Hole (Academic Lead)	<b>Co-Investigator(s)</b>	Metcalfe, R. (PhD Intern)
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>			
<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>	Stainton, T., Hole, R.	<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>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>	Baumbusch, J.	<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>Hole, R., Schnellert, L.</b>	<b>Co-Investigator(s)</b>	<b>Stainton, T.</b>
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Community Living Society, Massey Theatre Society		
<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>Hole, R.</b>	<b>Co-Investigator(s)</b>	Reid, C. <b>Stainton, T.</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, ASPIRE, Unity WISE Employment Solutions		
<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>Olsen, L.</b>	<b>Co-Investigator(s)</b>	Mc Kellin, W Collet, J.P. Gititmoghaddam, M Glegg, S Nault, T <b>Hole, R</b> Miller, A McKee, W Whitehurst, D Tatarenko, J Moore, S McGinley, S Faulkner, G Weber, R Banack, H Zwicker, J
<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>Olsen, L</b>	<b>Co-Investigator(s)</b>	McManus, A <b>Hole, R</b> Iarocci, G Brussoni, M
<b>Collaborators &amp; Partner Organizations (Knowledge Users and Policy Makers)</b>	Autism Okanagan, Canucks Autism Network		
<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 - 2024
<b>Principal Investigator(s)</b>	<b>Hole, R</b>	<b>Co-Investigator(s)</b>	Barnes, S Bottorff, J Crawford, C Domene, J <b>Schnellert, L</b> <b>Stainton, T</b> Williamson, R Wise, A Young, R
<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

- 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 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.

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

- Ji Lixin, Shandong University, Jinan China

### UBC Vancouver Work Learn Students



As part of their work/learn experience with the CIIC and in addition to their role as project research assistants, Alejandra Duarte and Pam Lozano, MSW students, accepted an invitation from the Self Advocacy Leadership Network to spend the Winter term supporting and contributing to their work.

*Working with CIIC and the Self Advocacy Leadership Network(SALN) has been the biggest opportunity I have had to learn. Not only have I met people with whom I share some of my most important values, but also people who I admire and have learned a lot from. I have learned a lot about Canadian laws, international movements regarding people with disabilities and emerging supports and programs. I am thankful for CIIC as it allowed me to connect with so many individuals and as William Hartnell said, “As we learn about each other, so we learn about ourselves”. I feel extremely grateful for this opportunity as it allowed me to grow professionally, academically and personally.*

*~ Alejandra Durate, MSW Student*

## 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
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 rural and 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,</b> Y. Lunsky
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</b> C. Reid
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>R. Hole</b> <b>L. Schnellert</b>	R. Irwin V. Magnat
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
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
Sue Sterling-Bur	IGS PhD	Understanding Giftedness Through <i>Nle?kepmx</i> Stories	J. Armstrong <b>R. Hole</b>	B. Tehwei M. Kovach

## Publications, Reports, Presentations and Videos

April 2021 – March 2022. CIIC researchers are highlighted in **bold**; students are underlined.

### Journal Articles

**Baumbusch, J.** & Lloyd, J.E.V. (early view, Feb 2022). Research priority setting with parents of students with learning exceptionalities and disabilities. *British Journal of Special Education*, 1-21.

**Baumbusch, J.**, Lloyd, J. E. V., Lamden-Bennett, S. R. \*, & Ou, C. (early view, Jan 2022). The unintended consequences of COVID-19 public health measures on health care for children with medical complexity. *Child: Care, Health and Development*, 1–9. doi: 10.1111/cch.12968

Breau, G., Thorne, S., **Baumbusch, J.**, Hislop, T. & Kazanjian, A. (early view, Jan 2022). Family physicians' and trainees' experiences regarding cancer screening with patients with intellectual disability: an interpretive description study. *Journal of Intellectual Disabilities*. doi: 10.1177/17446295211044041

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

Cook, S. & **Hole, R.** (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>  
doi: 10.1111/1467-8578.12405

**Hole, R.**, **Schnellert, L.**, & Cantle, G. (2022). Sex: What's the big deal? Exploring individuals' with intellectual disabilities experiences with sex education. *Qualitative Health Research*. 32 (3), 453 – 464.  
<https://doi.org/10.1177/10497323211057090>

Linehan C, Araten-Bergam T, **Baumbusch J**, **Stainton, T** et al. (2021) 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. HRB Open Res 2020, 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

**Schnellert, L.**, Tidey, L., & **Hole, R.** (Online July 2021). "You have the right to love and be loved": Participatory theatre for disability justice with self-advocates. *Qualitative Research*. Thousand Oaks, CA: SAGE. <https://doi.org/10.1177%2F14687941211034963>

Shannon, C., **Olsen, L.**, **Hole, R.**, & Rush, K. (May 2021). "There's nothing here": perspectives from rural parents promoting safe active recreation for children living with autism spectrum disorders. *Research in Developmental Disabilities*, 115, 1 - 10. <https://doi.org/10.1016/j.ridd.2021.103998>

**Stainton, T.** (2022). The beginning of the end of the great confinement: Institutional scandals and inquiries in the immediate post-world war II era. *British Journal of Learning Disabilities*, 1– 8.  
<https://doi.org/10.1111/bld.12460>

## Research Reports

**Hole, R., Reid, C., & Mudde, L.** (January 2022). IMPACT Cohort 2 Evaluation. *Ministry of Social Development and Poverty Reduction & The BC Employment Network*. 57 pages.

**Hole, R., Stainton, T., Christianson-Barker, J., & Asselin, R.** (2022). Accessibility standards supporting integrated employment for employees with intellectual disabilities: A scoping review. UBC Canadian Institute for Inclusion and Citizenship. 38 Pages.

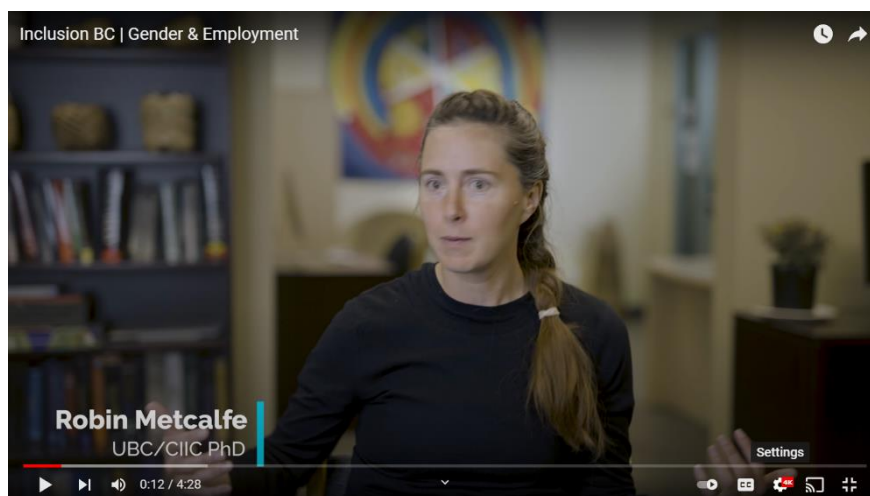
**Stainton, T., Hole, R., Sharma, R., Woolgar, L., et al.** (2022). Advancing Equal Access Jurisdictional Scan - Employment Standards for Intellectual and Developmental Disability. UBC Canadian Institute for Inclusion and Citizenship. 80 pgs.

## Other Knowledge Translation and Knowledge Mobilization Outputs

**Morris, R., Borja, C. Stainton T.** (2021) Microboards, Social Capital and Quality of Life. Infographic. CIIC.

**Stainton, T., Hole, R., Metcalfe, R., & Woolgar, L.** (2021). *Supporting Siblings: A New Path to Financial Security*. UBC Canadian Institute for Inclusion and Citizenship (2021). CIIC. 77 pgs.

*Employment Matters! Gender Matters!* (2022). Verschoor, K., and Hole, R. (producers). One Island Media. A partnership between Inclusion BC and the UBC Canadian Institute for Inclusion and Citizenship. <https://youtu.be/kT4P1qbBBkg>



**Stainton, T.** (2021) Social Justice's Poor Cousin: Disability, MAiD and Social Work. *The Social Lens: A Social Work Action Blog*. Oct. 7, 2021. <https://socialwork.ubc.ca/news/social-justices-poor-cousin-disability-maid-and-social-work/>

**Stainton, T.** Brief to the Commission Spéciale sur l'évolution de la Loi concernant les soins fin de vie National Assembly of Quebec. May 25, 2021. <http://www.assnat.qc.ca/en/travaux-parlementaires/commissions/CSSFV/mandats/Mandat-44835/memoires-deposes.html>

## Published Abstracts

**Baumbusch, J.,** Lloyd, J.E.V., Bennett, S. (2021). Understanding the impact of COVID-19 on healthcare for medically-complex children and youth. *Paediatrics and Child Health*, 26 (Supplement 1), e75.

Cook, S., & **Hole, R.** Building better services for people with an intellectual and/or developmental disability and multiple complex needs post-COVID-19. *Journal of Applied Research in Intellectual Disabilities*, 1238-1238.

Linehan, C., Araten-Bergman, T., **Baumbusch, J.**, Birkbeck, G., Cui, J.A., Gimenez, M.G., Gormiero, T., Mirfin-Veitch, B., Nolan, A., Stainton, T., Tideman, M. (2021). Caregivers' experiences of COVID-19 in different living arrangements for people with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 1252-1252.

## Publications Submitted

**Hole, R., Schnellert, L., & Tidey, L.** (submitted to QI December 2021). Topic: Ethics in research-based theatre: Stories from the field. *Qualitative Inquiry*. Special Issue editors: S. Cox, M. Guillemin, & M. Prendergast.

Marquis, S., O'Leary, R., Hayden, N. & **Baumbusch, J.** (revised and resubmitted, January 2022). A realist review of programs for siblings of children who have an intellectual/developmental disability: implications for current and future support. *Family Relations*.

Tidey, L., Schnellert, L., & Hole, R. (submitted March 15, 2022). "Everyone should get the chance to love": Sexual health education and disability research-based theatre with self-advocates. *The Canadian Journal of Human Sexuality*.

## Conference and Invited Presentations, Podcasts and Webinars

**Baumbusch, J.,** Clancy, A. & Jokisch, C. (March 31, 2022). Understanding the impact of COVID-19 on the mental health of parents and caregivers of children and youth with support needs. *Mental Health Research Canada: Spotlight on Research*. Online.

**Baumbusch, J.,** Lloyd, J.E.V. & Lamden-Bennett, S.R. (June 30, 2021). Understanding the impact of COVID-19 on children with medical complexity and their families. Paper presented at the 15<sup>th</sup> *International Family Nursing Conference*. Online.

Cook, S., & **Hole, R.** (2021). Building better services for people with an intellectual and/or developmental disability and multiple, complex needs post-COVID-19. Congress 2020: *International Association for the Scientific Study of Intellectual and Developmental Disabilities*. [Virtual Conference]

**Hole, R.** (September 27, 2021). The Future Generation- Make the Way for Youth Transitions. *The Canadian Association of Supported Employment*. (Virtual Conference)

**Hole, R.** (April 20, 2021) IMPACT: Youth Employment Research Project – Research & Ethics Training. Online. [Audience – knowledge users\community researchers]



**Hole, R., & Schnellert, L.** (May 20, 2021). Transitioning Youth with Disabilities and Employment. *BC Council of Administrators of Inclusive Support in Education*. Virtual via Zoom.

**Hole, R., Reid, C., & Mudde, L.** (Jan. 11, 2022). IMPACT Findings – Cohort Two. *Focus Disability Network Society*. Virtual via Zoom.

**Hole, R., Reid, C., & Mudde, L.** (Jan. 17, 2022). IMPACT Findings – Cohort Two. *BC Employment Network*. Virtual via Zoom.

**Hole, R., Schnellert, L., & Cantele, G.** (2021 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*. (Virtual Conference).

Metcalfe, R., & Hole, R<sup>SR</sup>. (June 30, 2021) Review of the literature informing home share and similar independent community living residential options. *Community Living British Columbia Senior Management Team*. (Microsoft Teams).

Metcalfe, R., & Hole, R<sup>SR</sup>. (May 3, 2021). Review of the literature informing home share and similar independent community living residential options. *Community Living British Columbia Senior Management Team*. (Microsoft Teams).

Moore, S., Butler, D.L., & Schnellert, L. (2021, June). Transforming Inclusive Education for Students with Intellectual Disabilities in Secondary Schools. *Paper presented at the annual meeting of the Canadian Society for Studies in Education*. Online.

**Stainton, T.** (April 16, 2021). Introduction to Disability. *Vancouver Neighbourhood Houses*.

**Stainton, T.** (Feb. 22, 2021). Supported Decision Making and Persons with Severe and Profound Intellectual Disability. *IASSIDD Virtual Conference, Sydney Australia* (Virtual).

**Stainton, T.** (June 9, 2021). Assisted Suicide and Intellectual Disability: A review of risks and vulnerabilities. *IASSIDD Europe Amsterdam* (Virtual).

**Stainton, T.** (June 9, 2021). Webinar on Self Directed Supports. *Citizen Network*.

**Stainton, T.** (May 25, 2021). Invited Testimony. *Quebec National Assembly End of Life Committee*.

**Stainton, T.** (Nov. 3, 2021). Supported Decision Making. *AIDE Canada*. Webinar.

Tidey, L., Faris, D., Gunkel, L., Pietras, A., **Schnellert, L., Hole, R., Nelson, J. A., & Gold, B.** (2021, June 10/11). Disability Justice in Applied Theatre: What Covid-19 Reveals about Accessibility in the Arts. [Conference panel session]. *Canadian Association of Theatre Research*. (Virtual).

Tidey, L., **Schnellert, L., & Hole, R.** (October 13-15, 2021). "Everyone should get the chance to love": Sexual health research-based theatre with self-advocates. (Conference Session). *Canadian Sex Research Forum*. Virtual

## Poster Presentations

**Baumbusch, J.,** Lloyd, J.E.V, & Lamden-Bennett, S.R. (June 23-25 2021). Understanding the impact of COVID-19 on healthcare for medically-complex children and youth. Poster presented at the *Canadian Paediatric Society Virtual Conference 2021*. Online.

**Schnellert, L.** (August, 2021). Keynote Presentation. Self-determination and student voice. *BC Family Support Institute Annual Conference*. Online.

**Schnellert, L.** (November, 2021). Keynote Presentation. Collaborating for inclusion. *Brockville and District Association for Community Involvement (Ontario)*. Online.

Sekhon, S., [Kaur, N.](#), & **Hole, R.** (July 5 – 9, 2021). Field realities in the Global South: Practicing reflexivity with marginalized populations. *20<sup>th</sup> Annual Thinking Qualitatively Virtual conference*. University of Alberta, International Institute for Qualitative Methodology and UBC Okanagan School of Nursing.

Tidey, L., **Schnellert, L.**, & **Hole, R<sup>SR</sup>**. (November 2021). “Everyone should get the chance to love”: Sexual health research-based theatre with self-advocates. *Canadian Sex Research Forum*. Poster presentation (Virtual).

## Media

**Baumbusch, J.** (June 23, 2021). CBC (Reporter: Bethany Lindsay): “Families’ ‘worst fear’ realized in investigation into Victoria charity for adults with disabilities. Available at: <https://www.cbc.ca/news/canada/british-columbia/bc-qarth-homer-society-families-1.6076299?cmp=rss>

**Stainton, T.** (October 7, 2021). [Social Justice’s Poor Cousin: Disability, MAiD and Social Work](#)

**Stainton, T.,** (May 25, 2021) [Tim Stainton appears before Quebec National Assembly Committee on Medical Assistance in Dying](#)

# 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 in 2023.

### Policy, Practice and Ethics

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

**Co-Lead: Dr. Rachele 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. Rachele 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, 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**

The Inclusive Education research stream is comprised of university faculty, educators, self advocates, and family members 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 2023.

## Research Project Descriptions & Selected Highlights

### Ableism and Employment Equity

Funded by BC's Office of the Human Rights Commissioner



British Columbia's  
**Office of the Human Rights  
Commissioner**

While federal and now provincial legislation aims to improve accessibility for people with disabilities, including employment as a priority area, barriers still remain. Discrimination in employment on the basis of disability continues to be the highest source of complaints at the B.C. Human Rights Tribunal. This short term research project is delving into the intersection of disability and employment equity in order to understand: types of employment barriers (obstacles to entry and to inclusion and accommodation once hired) in relation to different forms of disability; intersecting forms of discrimination experienced by people with disabilities; impacts on individuals, firms and society; and the success or failure of small- and large-scale interventions.

### Understanding the Impact of Covid-19 on Parents Caring for Children and Youth with Medical Complexity

Funded by a Canadian Institute for Health Research: Operating Grant

For the first time in living memory, there is a global pandemic — COVID-19 — that affects the entire population. Within this context, the vulnerability of certain groups is amplified, including children and youth with medical complexity. The health, education, and social lives of these children and youth, and by extension their families, are shaped by a complex system of federal, provincial and local policies. In a rapidly evolving pandemic situation, the needs of this population are at risk of being ignored, or worse, their rights being eroded. In this study, we will conduct an interpretive policy analysis examining parents' experiencing of caring for a child with medical complexity at this time. Findings from this study will generate a contextualized account of families' experiences, which can help inform policies and related supports.

This study employs interpretive policy analysis, an approach that examines the impact of policies on the everyday lives of people, in this case, families that include a child or youth with medical complexity. The setting for the research is British Columbia. Parents/guardians of medically complex children and youth are invited to complete a 30-minute online survey. A subset of these participants will take part in semi-structured interviews to gain greater insight into their experiences.

### 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 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.

## **Remote Supports as a Service Delivery Option for Individuals Accessing Community Living Services**

Funded by Vancouver Foundation, Community Living British Columbia, Mitacs

In partnership with the Community Living Society, Aspire, Spectrum, Inclusion Langley, and Inclusion BC, the CIIC is embarking on a research evaluation of a pilot project to test the efficacy and impact of using individualized approaches to supported living that combine both virtual/remote supports with in-person supports.

Our primary objective is to explore best practices when using remote supports to foster quality of life in individuals with I/DD living independently in the community.

Two overarching questions inform our research:

- Can the introduction of remote supports within the mix of support for individuals served through Supported Independent Living Programs in the BC community living sector lead to better quality of life outcomes for individuals served?
- What policy, organizational, and practice frameworks are required to safeguard the individual and ensure the long-term viability of this integrated service model?

Given the potential of remote supports to increase independence (less reliance on support workers entering an individual's home), enhance safety, provide on demand support virtually, and many possible other positive effects, learning how to effectively and ethically implement remote supports will inform our own learning. Moreover, it will offer timely and needed research to inform policy and practice locally, provincially, nationally, and internationally. That is, findings from this study will benefit other jurisdictions who have ventured into and/or are exploring the potential of remote support options as a complement to existing face to face delivery options in their supported independent living programs.

## **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.

## We Deserve to Work

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



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 intellectual and developmental disabilities. People with I/DD 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. Save the date for performances at the Massey Theatre in New Westminster November 18, 19, & 20, 2022 and at the World Supported Employment Conference in Vancouver in June 2023.

*Access and inclusion in creativity and self-expression is a fundamental right of all people. For much of the history of theatre making this access and inclusion has not existed. It is time for that to become a thing of the past. Such notions are challenging to our facilities, our funding models and our day to day methods of work in the performing arts professions. In order for adaptations to emerge, the sector must engage with self-advocates directly and in a sustained manner.*

*~ Jessica Schneider, Executive Director, Massey Theatre Society*

## 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 of 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 has included 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. This information has been used to prepare a Knowledge Synthesis Report on barriers, best practices and guidelines for people with intellectual disabilities throughout the four key cycles of employment. In June 2022, 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.

*The Canadian Institute for Inclusion and Citizenship has been an integral partner in our work for over a decade. CIIC's extensive contribution to research and knowledge on intellectual disability policy and practice has enabled Inclusion Canada to deepen our work in strengthening families, defending rights, and transforming communities. Inclusion Canada is fortunate and grateful to work with an established research institute dedicated to our shared mission of advancing the inclusion and human rights of people with an intellectual disability and their families.*

*~ Krista Carr, Executive Vice President, Inclusion Canada*

## 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. The project involves three cohorts of youth over three years. Eight agencies of the BC Employment Network are in their third year of implementing summer youth employment programs. Outcomes reveal an increase in overall paid and unpaid work experience through the youth's engagement with IMPACT. In Year 1 (2020), 72 youth participated and 72.2% of the youth gained employment experience. In year 2 (2021), 91 youth participated and 76.9% of the youth gained employment experience. In addition, the results indicate an increase in domains that are predictors of getting a job and keeping a job, and increases in self-assessed knowledge about employment. Agency interventions with participating youth improved the youth's unique strengths and interests related to employment and skills.

The project reports from Year 1 and Year 2 are available on the CIIC website.





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

**The TYDE 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. Research consistently supports that intervening early when young adolescents with developmental disabilities are transitioning from school to adult life translates to positive employment outcomes. Further, research demonstrates that 1) experiences with inclusive education, 2) positive parental expectations for employment and/or post-secondary education, 3) greater levels of self-determination among transitioning youth with developmental disabilities, and, 4) early work experience are predictive of higher employment outcomes. Based on these four domains, we have created 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.

The **overarching learning outcomes** of the TYDE Program are:

- Youth create a plan for getting and maintaining meaningful employment.
- Youth develop their capacity to have a say in and make decisions about their lives and future (“nothing about us without us”).
- Family members/caregivers develop knowledge and skills to support your youth in creating a plan for transitioning to meaningful employment.

#### Where have we been?

From January to June 2022, we conducted two pilot projects: one with a community living organization supporting transitioning youth and one in partnership with some schools.

#### Some comments from youth participants:

- *“I like how it is very visual. I like that you can give your true voice.”*
- *“I learned how to get a job efficiently”*
- *“I learned about self-advocacy and goal and future planning.”*
- *“That employers should give people with disabilities as much of a chance as anyone else when it comes to the job.”*
- *“I like how it had people who have already experienced it talk about their experience.”*
- *“ [I learned...] what my strengths are.”*
- *“The questions and activities about the tasks were good; it helped me learn what I’m good at.”*

A comment from an inclusive education teacher:

- “Wow, this program looks incredible, and yes, [Name of Student] can most definitely use it for her Career Life Connections course. It looks to me like it would cover most or all of the courses that we have.”

Where are we going next?

In the fall of 2022 we will be launching a fourth cohort of youth and parents/caregivers in partnership with a number of school districts and other community organizations supporting transitioning youth with developmental disabilities on their employment journey. Stay tuned for more details.

The screenshot displays a user interface for a learning management system. On the left is a green sidebar with the heading "Parent" and a dropdown arrow. Below it, the section "Introduction to TYDE" is expanded, showing a list of items: "Introduction video", "Dyad activity", "Resources", "Activities in this unit", "Glossary", "External resources", and "References". A "Logout" link is at the bottom of the sidebar. The main content area has a top navigation bar with icons for home, smile, star, target, and settings. Below this, the title "Introduction to TYDE" is followed by a green checkmark. The "Introduction video" is selected and is playing. The video frame shows an illustration of a woman and a young girl sitting at a table with a laptop. The text "do an activity together" is overlaid on the video. The video player includes a play button, a progress bar showing 11:04 / 16:41, and standard video controls like volume, full screen, and a menu icon.

## 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.

There are several specific objectives associated with this goal:

1. We will identify parents/guardians\* and educators'\* perspectives on the impact of COVID-19 on inclusive education in BC. (*\*Update as of Feb, 2021: The parent survey has already been completed; the educator survey is currently underway*)
2. We will develop recommendations for policies and programming to support inclusive education during and after COVID-19.
3. We will use a range of knowledge uptake strategies to communicate our findings to students, parents, educators, and policy/decision-makers in the public-school system.

Ultimately, this project will advance partner organization [BCEdAccess](#)' leadership role advocating for inclusive education to the benefit of students with disabilities and complex learners across BC. The project will be theoretically informed by intersectionality, a perspective that allows us to examine how social locations shape the perspectives and experiences of those engaged in inclusive education and avoids homogenizing this into one population.

## Understanding and mitigating the impact of COVID-19 on the mental health of parents and caregivers of children and youth with support needs in British Columbia

Funded by Mental Health Research Canada (MSFHR & MCFD)

From MSFHR: While COVID-19 has affected the mental health of all Canadians, those with complex family needs have struggled even more. The strain is especially great on parents and caregivers of children and youth with support needs experiencing (or at risk of) developmental delay or disability.

Research studies about the impact of the pandemic on parental mental health tend to view parents of children with support needs as a homogenous group, or they tend to explore separate diagnostic categories (such as Autism Spectrum Disorder and medical complexity).

Lead investigators Dr. Jennifer Baumbusch and Angela Clancy will not replicate existing studies but will extend what is currently known, particularly in the context of British Columbia. The investigators and their team will compare mental health impacts with a larger pan-Canadian sample. They will also compare mental health impacts within the sample of parents of children with support needs based on diagnostic categories, individual factors of parent and child (such as gender, age, race, ethnicity, education, family structure and household income), and community factors (such as geographic location and size of community) — and compare between these categories.

The goal is to identify specific strengths and vulnerabilities of different sub-groups that can be used to customize supports. The BC research team will also explore existing knowledge about programs (such as peer-to-peer and one-on-one counselling) and promising practices (such as virtual/tele-health and enhanced respite) that help mitigate mental health impacts and foster family resilience.

Lead investigators Dr. Jennifer Baumbusch and Angela Clancy (Family Support Institute of BC), together with Chelsea Jokisch, a patient with lived experience, share their key discoveries and insights so far, in this March 2022 webinar hosted by Mental Health Research Canada. [Watch the video interview here:](#)



# Team Members

## Co-Directors

- Dr. Rachele Hole, 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. 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 Assistants and Staff

### Research Assistants/Students and Work Study Students

- Alejandra Durate, MSW, Work Learn Student
- Belinda Chi, PhD Student, We Deserve to Work Project
- Emily Giroux, TYDE
- Jenna Christianson-Barker, MSW, Advancing Equal Access for People with Disabilities in the Workforce and We Deserve to Work Projects
- 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
- Pam Lozano, MSW, Work Learn Student
- Rae Morris, PhD, Advancing Equal Access for People with Disabilities in the Workforce Project
- Ramona Sharma, MSW, Advancing Equal Access for People with Disabilities in the Workforce Project, Ableism and Employment Equity Project
- Robin Metcalfe, MSW, TYDE Project
- Sandra Polushin, PhD (Simon Fraser University), TYDE Project (UBC GAA)
- Sue Sterling-Bur, PhD Candidate – TYDE Project

*Working with the Self Advocacy Leadership Network (SALN) to create and update policies now that they have become a society, and through CIIC on the Jurisdictional Scan was eye opening for me as it assured me that this is an area that I am passionate about and would love to continue to learn more from. It additionally gave me insight on the skills required for this type of work, and helped me understand the diversity of work and its importance.*

*~ Pam Lozano, MSW Student*

## Research Staff

- Aidin Niavarani, Application Lead Developer, TYDE Project

## Project Contractors

- Jessica Ann Nelson, We Deserve to Work, Co-Producer / Co-Director
- Jordy Matheson, We Deserve to Work
- 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

## 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 Steering Committee
- Chelsea Rinquinha, Self Advocate Leadership Institute Planning Committee
- Colton Sterling-Moses, TYDE Project, Provincial Advisory Committee
- Dana Faris, We Deserve to Work Project Steering Committee
- Darryl Harrand, Self Advocate Leadership Institute Planning Committee
- Dave Sherritt, Self Advocate Leadership Institute Planning Committee
- David Johnston, Self Advocate Leadership Institute Planning Committee
- Joanne Gauthier, Provincial Advisory Committee
- Joanne Gauthier, Self Advocate Leadership Institute Planning Committee
- Jose Figueroa, TYDE Project
- Kaitlin Smith, TYDE Project
- Kara Anderson, Self Advocate Leadership Institute Planning Committee
- Kimberley Earl, Self Advocate Leadership Institute Planning Committee
- Kya Bezanson, Self Advocate Leadership Institute Planning Committee
- Kyle Youmans, TYDE Project
- Larissa Gunkel, We Deserve to Work Project Steering Committee
- Lorie Sherritt, Self Advocate Leadership Institute Planning Committee
- Michael McLellan, Self Advocate Leadership Institute Planning Committee
- Raymond Edinger, Self Advocate Leadership Institute Planning Committee
- Richard McDonald, Self Advocate Leadership Institute Planning Committee
- Shameera Rosal, TYDE Project
- Shelley Decoste, Self Advocate Leadership Institute Planning Committee
- Sherwin Strong, Self Advocate Leadership Institute Planning Committee
- Tami Pederson, Self Advocate Leadership Institute Planning Committee
- Vicky Abbott, Self Advocate Leadership Institute Planning Committee

A very special thank you to the self advocates who were interviewed for the Gender Matters video.

# 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 (until January 2021)
- 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
- Jennifer Baumbusch, UBC CIIC Research Lead
- Joanne Gauthier, BC People First
- Joshua Myers, BC Centre for Ability
- Karla Verschoor, Inclusion BC
- Leyton Schnellert, UBC CIIC Research Lead
- Lise Olsen, UBCO CIIC Research Co-Lead
- 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 CIIC currently has research space in ARTS 368 at UBC Okanagan. The space is comprised of one office for co-director, Dr. Hole, a small conference room, and an open area with four work stations for research staff and assistants. Space has been designated for the CIIC on the 7<sup>th</sup> floor of the new UBC Okanagan downtown campus.

### 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	2021/2022	\$50,000
Institute Funding from UBC Vancouver Faculty of Arts	2021/2022	\$25,000

## Community Engagements & Participation

### Self Advocate Leadership Institute

A planning committee of 20 self-advocate community leaders from around the province has been meeting monthly to co-design the 2023 Self-Advocate Leadership Institute (Conference). The committee wants to restore power to people with disabilities through a fully accessible learning event for people with disabilities by people with disabilities.

Inclusion BC and the Canadian Institute for Inclusion and Citizenship provide administrative support to the committee. The event is tentatively set for Summer 2023 on the UBC Okanagan Campus and was initiated following the success of the 2018 BC Leadership Institute for Developmental Disabilities to support the next generation of leaders in the community living sector.

### Representation on Community and Government Committees

- Baumbusch, J. Invited National Working Group Member, Royal Society of Canada Working Group on Recommendations for COVID-19 and Neurodevelopmental Disabilities. Co-led writing recommendations on inclusive education. December 2020 – April 2021
- 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, R. Member of the Inclusion Canada Employment Equity Act Review Committee. March 2022 – ongoing.
- Hole, R. Reimagining Community Inclusion Employment Work Group – BC Ministry of Social Development and Poverty Reduction – [committee member] – March 2021 – Aug. 2021.
- Hole, R. Committee Member Feb. 2022 – June 2023. World Conference for Supported Employment Planning Committee). Conference to be held in Vancouver, June 2023
- Hole, R & Stainton, T. Canadian Leads and Founding Members, Citizen Network. International Network supporting Citizenship and Inclusion based in the UK.
- Stainton, T. Co-Chair, Canadian Association for Community Living Task Force on Medical Assistance in Dying.
- Stainton, T. Fellow and Member, International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD).
- Stainton, T. Member, Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA) Employment Curriculum Development Committee.



- Stainton, T. Member, IASSIDD Ethics Special Interest Research Group. Expert Advisory Group on Medical Assistance in Dying (MAiD). (International)
- Stainton, T. Member, Knowledge Core Committee, Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.(Canada)
- Stainton, T. Expert Advisory Group on MAiD (Medical Assistance in Dying) and Persons with a Mental Disorder, 2020.
- Stainton, T. Member, Accessibility Legislation & Covid-19 Advisory Committee, BC Ministry of Social Development and Poverty Reduction.
- Stainton, T. Member, Inclusion Canada Working Group on Income Security.
- Stainton, T. Advisor. Inclusion Canada. Medical Assistance in Dying (MAiD)
- Stainton, T. Member, Advisory Group on Business Case for IDD Medical Consultant. Advocate for Service Quality, BC Ministry of Social Development and Poverty Reduction.
- Stainton, T. Advisor, Vulnerable Persons Standard.
- Stainton, T. 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.
- Stainton, T. Member, IASSIDD working group on development of position statements.
- Stainton, T. Member, Accessibility Legislation & Covid 19 Advisory Committee, BC Ministry of Social Development and Poverty Reduction.

## Consultations

- Stainton, T. Consultation with National Disability Organizations on MAiD/Bill C7 Ongoing.
- Stainton, T. Expert Witness, RE: 'CB', Laxton-Gibbens. April 22, 2021 (Report and consult).
- Stainton, T. Expert Witness, RE: 'EH', Pacific Medical Law, May 21, 2021. (Report and consult).
- Stainton, T. Expert Witness, RE: 'KA', Pacific Medical Law, Jan. 2022. (Report and consult).

## Citizen Network

Student Research Assistants Alejandra Durate and Robin Metcalfe have collaborated to create



some content that is accessible in Spanish and English as a way of promoting inter-connections between people and organisations across the Americas. They will generate summaries of research articles in English and Spanish that may be of interest to Citizen Network members. They have also hosted two interviews, one in English and one in Spanish, which we recorded and are captioned in both English and Spanish. Dr. Karen Bopp, Director of Provincial Outreach with the Centre for Interdisciplinary Research and Collaboration in Autism, was interviewed about the achievements of the free, online, self-paced professional development programme [Autism & Neurodiversity in the Workplace](#). A number of organisations in South America with interests that connect well with Citizen Network have been contacted and through this effort an interview was hosted with [La Red Regional por la Educación Inclusiva de Latinoamérica](#) (The Regional Network for Inclusive Education in Latin America). The interviews were recorded and will be available on the CIIC website in the Fall of 2022.

## 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**
- Tim Stainton, Co-Editor, **British Journal on Learning Disabilities, Special Issue on History**

## 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.

- ASPIRE
- Autism Intellectual Disabilities National Resource and Exchange (AIDE) Network.
- Autism Okanagan
- Autism Society of BC
- BC Centre for Ability
- BC Centre for Employment Excellence
- BC Council of Administrators for Special Education
- BC Ed Access
- BC Employment Network
- BC Ministry of Education
- BC People First
- BC Representative for Children and Youth
- BC's Office of the Human Rights Commissioner
- 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
- Massey Theatre Society
- Ministry of Children and Family Development (BC)
- Ministry of Social Development and Poverty Reduction (BC)
- North Vancouver School District
- 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
- Spectrum Society for Community Living
- Spirit of the Game Society
- STEPS Forward
- Sun Peaks Adaptive Ski Program
- Sunny Hill Health Centre
- The Regional Network for Inclusive Education in Latin America
- Therapeutic Recreation, Douglas College
- UBC Studios
- Unity WISE Employment Solutions
- University of Calgary
- University of Kansas
- Vela Canada
- Victoria Native Friendship Centre

# Goals for 2022 – 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.
- Secure research (and other) funding to provide undergraduate, graduate, and post doctoral 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 for 2022 - 2023

- 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)
- Present research findings at annual Inclusion BC Conference/Learning Event
- Increase user accessibility features of Institute’s website
- Develop and distribute an online newsletter
- Develop skills and expertise in innovative Knowledge Translation / Knowledge Mobilization 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
- Provide consultation and advice to the sector as requested
- Conduct research for CLBC and the community living sector, including the following:
  - Enhanced impact evaluation frameworks and reporting on activities engaged in by CLBC and the sector;
  - A minimum of one scoping review of the literature each year as determined by CIIC and CLBC; and
  - A minimum of one pilot research project to inform policy and practice as determined by the CIIC and CLBC.

## Contact Information

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