



Purpose of the Note

The [MacEachen Institute for Public Policy and Governance](#) and Dalhousie's [Health Law Institute](#) hosted a targeted workshop on November 18, 2021 to discuss community-academic partnerships formed to advance disability policy reform. The goal was to bring together a small group of people from the university and the wider disability-advocacy community to discuss how health and disability research can contribute to social justice movements, with a focus on how partnerships established in this context may be leveraged to inform international human rights law monitoring and reporting processes affecting people with disabilities. This Briefing Note summarizes the discussions that took place and identifies recommendations.

This event was an opportunity to discuss challenges faced in building these partnerships which aim to more inclusively create, reform, monitor, and enforce human rights law and policy, and to discuss strategies to meet these challenges. Nineteen participants were invited. They included persons involved in the negotiation and global implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other disability-based social movement organizing, as well as lawyers and former politicians, and scholars in law, social work, political science, occupational therapy, nursing, health equity, and sociology and social anthropology.

Speakers

[Dr. Keiko Shikako](#), McGill's Canada Research Chair in Childhood Disability, was invited to present to the group and comment on her work in relation to the UNCRPD and the United Nations Convention on the Rights of the Child (UNCRC).

[Steven Estey](#), a former Human Rights Officer for the NGO Disabled Peoples' International (DPI), was central to Canada's participation in the negotiation and drafting of the CRPD. Mr. Estey has subsequently played various roles advocating and consulting with governments, UN agencies and regional human rights bodies as well as NGOs on ratification, monitoring and enforcement of the CRPD. Mr. Estey was invited to reflect on the presentation and provide insights from his own knowledge and experiences promoting democratic participation of people with disabilities in Nova Scotia, Canada, and internationally.

Academic Participation in Social Justice Organizing

Partnerships between the community and university can lead to more socially relevant research contributing to advancements in equitable and just social policy. These relationships take considerable investments of time and energy on both sides, and it can be challenging to coordinate and mutually reinforce the interests, goals and strengths of both academics and community members. This event was an opportunity for all to discuss challenges faced in building these partnerships to more inclusively create, reform, monitor, and enforce human rights law and policy, and to discuss strategies to meet these challenges.

What We Recommend

- Academics, including those who are disabled and allies of the disability movement, can support disabled persons organizations in their advocacy work and help build their own capacity and that of disabled individuals and organizations who may otherwise be sidelined in the policy process.
- It is especially important for academic researchers to reach out to community members, and to be open to conversations and creating opportunities for meaningful collaboration. Academics need to be available and informed by what is being asked of them by community members and strive to find ways to legitimize community organizations as researchers in their own right.

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About the MacEachen Institute

The MacEachen Institute for Public Policy and Governance at Dalhousie University is a nationally focused, non-partisan, interdisciplinary institute designed to support the development of progressive public policy and to encourage greater citizen engagement. Constance MacIntosh, of the MacEachen Institute, was a co-organizer of this event.

About the Health Law Institute

[The Health Law Institute \(HLI\)](#) seeks to understand, use and adapt law and policy to improve health and well-being through scholarship, education and public service. The institute is based out of Dalhousie's Schulich School of Law. Sheila Wildeman, of the HLI, was a co-organizer of this event.

Author

Kaitlynn Lowe, Research Assistant for the MacEachen Institute for Public Policy and Governance

Contact

For more information on this research,

What We Recommend (continued)

- Researchers should recognize that while policy can be informed by evidence, it is misleading to suggest that it is ever fully “evidence based”, where this is taken to mean that there are no value judgments or interests involved. Specific attention must be paid to what evidence is used, where it comes from, how it is prioritized, and who it benefits. Community members have important insights into how to approach these issues.
 - Disaggregated data is critically important for policy work. However, it is still largely unavailable regarding the situation and experiences of people with disabilities, despite many calls for action in this area.
 - Follow-up with community on the part of academic researchers is an important part of the partnership process. Attention must be paid to ensuring that ongoing concerns and priorities of on the ground advocacy groups are identified and addressed.
 - There is a need to reduce the siloing of knowledge production and mobilization, both among academic disciplines and as between academics and the wider public.
- Academic researchers should recognize the power dynamics inherent in working with community and be diligently attentive to avoiding inadvertently taking over the research process. This includes such primary matters as the framing of research questions.
 - Ongoing collaborations and conversations are important for fostering and maintaining relationships between academic researchers and the community. This demands dedicated resources, and so requires institutional commitment and the willingness of universities and funders to support such practices.
 - An important aspect of this work is compensating members of the community and organizations for their time and expertise, either as collaborators/co-creators or informants. It is important to establish (and advocate for, at the university and funder levels) flexible funding models to pay people appropriately and in ways that resist traditional researcher / research subject relationships and associated power dynamics.
 - There are many diverse functional needs to consider when facilitating cross-ability/disability communication in the context of university-community partnerships. Universal accessibility can be expensive but is key for meaningful and inclusive collaboration. The more often academic researchers budget for accessibility needs as a basic feature of research activities, the more normalized this practice becomes.
 - The UNCRPD and UNCRC should serve as frameworks for policy development, and researchers can assist in these processes by developing and validating corresponding tools and indicators for success such as [Bridging the Gap](#).

Presentation Academic Participation in Social Justice Organizing

Dr. Shikako is a Canada Research Chair in Childhood Disability. Her work focuses on disability and civil society participation and knowledge translation in research and policy making concerning marginalized populations including children with disabilities. She works with community and lived experience experts on person-centered law and policy work. She is an Associate Professor in the School of Physical and Occupational Therapy at McGill University

The goal of social justice is often to level the playing field, which means to remove barriers for full participation in society for everyone. There are key questions to consider when working in this area: What is social justice? What is knowledge and where does it come from? What can academics do? And most importantly - what can we do together?

Researchers can use information to create tools for action and to get information where it needs to be. Information from research can be used as a tool to drive independent thought, inform policymakers, foster multi-sectoral collaboration, uncover inequities, and to drive inclusive impact, facilitate evidence-informed innovation and best practices, and catalogue lived experiences. Research can be an opportunity to bring together voices and knowledge of people with lived experience with the goal of removing barriers in society.

In academic research, especially health research, knowledge often comes from rigorous experimentation and controlled clinical trials. This generates a false belief that this is the only knowledge that should be mobilized. Findings from experimentation can be disconnected from lived experience and not applicable to real life. Bridging the gap between knowledge from lived experience and academically generated knowledge can produce findings that are more applicable to the real world.

The [United Nations Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#) and [United Nation Convention on the Rights of the Child \(UNCRC\)](#) provide frameworks for both academics and civil society to use in setting research and advocacy priorities and informing policy analysis and development.

The UNCRC (1989) includes 54 articles all oriented toward creating a new, more just world for children. The UNCRPD (2006) was ratified by Canada in 2010 and was developed through a highly participatory process. There are intersections between the UNCRC and UNCRPD, but they rarely speak to each other within UN processes. It can be challenging to ensure respect for the evolving needs and experiences of children with disabilities as children and then as they become adults. There are additional intersections between the UNCRPD and other internationally recognized priorities such as the UN Sustainable Development Goals (SDGs). There are opportunities for Disabled People's Organization (DPOs) to engage embedded processes within the UNCRPD, such as country reports, consultations, and committee statements and recommendations.

There are also tensions between the UNCRPD and the UNCRC. For example, the institutionalization of children with disabilities is permitted under the UNCRC but not under the UNCRPD. Governments and UN bodies alike struggle to reconcile these two conventions regarding institutionalized children. A two-track approach is used at the UN level. At the federal level in Canada, issues relating to children, youth, and disability are distributed among different ministries, and the priorities of children and youth with disabilities can fall through the cracks.

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Presentation Academic Participation in Social Justice Organizing (continued)

Canada has ranked in the middle of countries with comparable income levels regarding the UNICEF Child Health indicators for the past 10 years. However, Canadian children are ranked as some of the unhappiest children in the world, and indicators for children with disabilities are worse. Many of these indicators are around health and well-being, including access to active transportation, vaccination, education, and healthy living. There are significant issues with the lack of data about children with disabilities in Canada, which are evident in Canada's most recent report to the UN. It is important to bring researchers, health care providers, educators, families, and children and youth together to ground research in lived experience. Families often have the best knowledge about what they need but it is challenging to direct concerns to the appropriate decision-maker or policymaker, especially when multiple jurisdictions are involved.

There are organizations that work to connect research and policy development, such as the [Child-Bright Policy Hub](#) and [ARCH: Disability Law Centre](#). The Child-Bright Policy Hub aims to understand Canadian public priorities related to children with disabilities, explore the representation of the UNCRPD and UNCRC, and identify directions for research and policy based on public consultation data. The Child-Bright Policy Hub conducted research into public consultation data from the [Accessible Canada Act \(2019\)](#) and highlighted that there was little information included about children with disabilities. There are opportunities to engage people with lived experience in international policy efforts, such as the World Health Organization (WHO) Urban Health Agenda 2030, UNICEF/WHO Global Report on Disabilities, and municipal and provincial partnerships. [Bridging the Gap](#) indicators identify structural processes and outcomes relating to the UNCRPD.

A disability inclusion lens is being applied to other policy areas, such as Disaster Risk Reduction (DRR). This highlights additional opportunities for people with disabilities to engage in policy development. The [Sendai Framework](#) calls for disability inclusion in all phases of DRR, including engagement, capacity-building, accessibility, data, and empowerment. The importance of this has been made evident throughout the COVID-19 pandemic, which has exacerbated existing inequities affecting people with disabilities.

There are key differences in timelines used by policymakers, academics, and community members. Information needs to be easy to digest, presented in a timely manner, and to be more effective, should align with or be responsive to the policy agenda. Information from research needs to be usable by both researchers and policymakers and bridge lived experience with research evidence. Understanding policy windows within the system can help identify opportunities to bring information forward. Dialogues are necessary to understand policy agendas at each level of government. A key strategy is to identify issues and compile research well in advance of the information being recognized as needed, as well as using that information to advocate for innovations in the policy-making agenda. However, there are also risks that information from research can be misinterpreted and used in unintended ways, especially if disabled people are left behind when the conversation continues.

There are many challenges relating to public consultations. It can be challenging to know what to ask members of the public and to accurately report on issues raised during a consultation process. Confusion about the roles and responsibilities of different levels of government also means that information provided may not be relevant to certain audiences and may result in jurisdictional confusion. Families often know what they need, but jurisdictional barriers and confusion sometimes mean their concerns are not addressed. Creating opportunities and space for children and youth to speak to their unique experiences is key.

Reflection by Steven Estey

Steven Estey was the National CEO of the Council of Canadians with Disabilities for two years, and continues to serve as needed. Mr. Estey is a former Human Rights Officer with Disabled Peoples' International (DPI). He was the DPI advisor to the Canadian delegation for the United Nations Ad Hoc Committee that drafted the UNCRPD between 2002 and 2006. He continues to be involved in the monitoring and reporting on the UNCRPD in Canada and abroad.

Mr. Estey has built a career working with academics and grassroots Non-Government Organizations (NGOs) in law and policy work domestically and internationally. In 2017 he established the Bill 59 Alliance in Nova Scotia, which brought together academics, NGOs, individuals with disabilities and their allies, to resist the legislation as drafted by the Government and reform the proposed accessibility legislation in Nova Scotia. Beyond his extensive work on the negotiation and global implementation of the CRPD, Steve also led work to include provisions for victim assistance in the 1996 international land mine ban treaty, or Ottawa Convention as it is often called. He was invited to comment on Dr. Shikako's presentation.

Following Dr. Shikako's presentation, Steve Estey offered reflections on her comments based in his own experiences and knowledge. Some of his comments are described below.

There are considerable problems caused by the lack of data. Efforts to meaningfully report on the UNCRPD has been undermined by the lack of data concerning both adults and children with disabilities.

This is not surprising to anyone who has been working in this field a long time, as often people with disabilities face discrimination because they are invisible to those who hold power. The lack of data reflects this reality.

People with disabilities represent [22% of the Canadian population](#), however, disability is rarely discussed as a human rights issue.

People with disabilities moved the UNCRPD forward. The Convention enables discussions about people with disabilities and human rights. At the end of the day, equality for people with disabilities will only be achieved if we are seen and listened to and part of the decision-making process.

Questions used to Guide Discussion

After the remarks from Dr. Shikako and Mr. Estey, the following questions were used to guide the workshop discussion, during which participants offered reflections on these questions and raised further points for discussion:

1. What challenges do university-community partnerships face in working together to inform domestic and/or international law and policy creation, reform, oversight, and enforcement?
 - a. You may wish to consider, for instance, power dynamics, tensions between lived experience and other bases of expertise, and other factors affecting community engagement, knowledge mobilization, or other processes. Responses may be focused on disability organizations or inclusive processes involving other groups experiencing marginalization and exclusion.
2. What are some strategies for meeting those challenges? I.e., how might we better support university-community partnerships to inform domestic and /or the interaction of domestic and international human rights processes?

What We Discussed

“Community” can mean different things to different individuals and groups. Researchers need to be deliberate about what “community” means in terms of research scope. They also must remain flexible to receiving and learning about other understandings of “community” from the grassroots level.

From the academic point of view, knowledge in different fields can be siloed, and so it can be challenging to understand the meaning or relevance of information coming from a different field than one’s own (e.g., health and law). There are also often exclusionary practices in place. Knowledge transfer between fields can feel like learning a different language, and what may be common sense in one field may seem foreign to another. It can also be challenging to find the time to do the work required to understand different types of knowledge and build relationships with people working in a different field.

It is important to build community-academic relationships in part because this allows shared creation of knowledge and expertise and mutual access to new information. That knowledge can be further mobilized across different organizations and levels of government. Starting projects with a particular research question or inquiry can sometimes lead to connecting with others needing similar information and the sources of knowledge and knowledge mobilization proliferate. It is especially important to reach out to people who are outside of our regular circle of contacts, and to be open to conversations and opportunities for collaboration. Ongoing collaborations and conversations are important to maintain relationships among academics and community members. Sometimes a different mindset is needed rather than simply more time. Academics need to be available and informed by what is being asked of us by community members. Follow-up is an important part of the research process and deserves specific attention, especially for on the ground advocacy. It can highlight how concerns that have been raised previously have been responded to, or not.

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What We Discussed (continued)

When looking to build community partnerships and conduct community-engaged scholarship, we often must wait on the will of government. This can be especially challenging when governments change. Navigating political shifts and changes is part of policy work, including finding ways to navigate ideological and value differences. Much of this work is founded on relationship building, which can be challenging due to the changing nature of staffing political and bureaucratic systems.

Disability needs to be part of mainstream discussion (not just siloed to specific “disability issues”) and partnerships with academics can support this. There is real value in academics working with NGOs to build capacity across society and it is important to find opportunities in research to connect with people with disabilities, including those situated across other forms of social oppression and marginalization, as disability is often neglected from conversations about intersectionality. It can be challenging for organizations supporting persons with disabilities to influence policy, as representatives and organizations are often poorly resourced. This is especially true at the national and international levels, as many large organizations will say they are “taking care of things”. However, it is one thing to provide medical aid or an assistive device, but another to have adequate social supports in place. For example, the Land Mine Ban treaty was the first international agreement that talked about the rights of the victims of war (1996). The Canadian Government would pay for rehabilitation, but people then would die of starvation because they lacked the necessary social supports.

One important aspect of this work is to fund people and organizations for their time and expertise. Community members and organizations cannot participate without the funds to do so, especially given the high intersection between poverty and disability. National Research Council funding can in some contexts be an opportunity to pay people for their time and experience. Researchers should consider flexible funding models to pay people appropriately as collaborators (co-creators of knowledge) or informants, and in light of individual circumstances. For example, when working with people accessing benefits such as income assistance, attention should be given to how payments may be structured to avoid claw backs and thus a reduction in their benefits. It can be hard to align process needs with post-secondary grants and other funding systems which place restrictions on ways to pay people, how much they can be paid, and what form they can be paid in (e.g., gift cards). There are additional rules around paying children to consider.

It is also important to budget for accommodations for various functional needs when planning research with people with disabilities. There are many diverse ways of moving and communicating to consider ensuring that the set-up for every meeting effectively enables cross-disability communication. This can be expensive but is key. The more we ensure the accessibility of research activities and the more often we budget for it, the more we normalize this practice.

Disaggregated data is very important for policy work; however, despite many calls for action, it is still largely unavailable with regard to the situation of people with disabilities. Data from the provincial and territorial levels is often neglected in international oversight reports, as many international committees are focused on information from the national level. The Canadian Survey on Disability also excludes data from people living on First Nations reserves or in congregate living facilities. There are discussions on conducting specific data collection about people with disabilities living on First Nations reserves. This approach had been called for by First Nations, rather than just adding questions to Canada Survey on Disability.

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What We Discussed (continued)

Different timelines for research can be necessary when working with the disability community. Robust consultation processes can take time, even working within one disability community. It can be challenging to navigate tensions within the disability community, including with regard to respectful and critically-informed language. There are additional challenges to use language from the community while still trying to speak the language of policymakers.

There needs to be a focus on navigating the power dynamics between post-secondary institutions and grassroots organizing. Often grassroots organizations are denied funding opportunities unless they are partnered with a post-secondary institution. Governments and post-secondary institutions often work together because their agendas align. Researchers need to consider what system transformation looks like and be honest about the space academics take from community organizers to fit projects into existing funding systems. Academic researchers need to recognize their complicity and be honest about this in their relationships with community organizations, and to pay focused attention on building authentic relationships with community organizations.

Activist knowledge and research are often not treated as legitimate research unless part of or associated with a post-secondary institution. Often, they are treated as sources of experience rather than legitimate knowledge. This relates to the thematic questions of what is knowledge and where does it come from? It is important to consider what research really is and what guides it, because it is not solely academic prerogatives. First voice groups should lead policy development and setting priorities. However, many of these organizations face capacity issues and it is especially important to ensure academics do not take over the research process in an effort to address the gap.

We need to find more ways to legitimize community organizations as researchers. For example, community organizations have led the way, with academic researchers in the minority, in the UNCRPD environment. Academic researchers need to be better equipped to conduct research in a way that supports the initiatives of community organizations, especially ones that are severely strained and serve populations that face many barriers to participation, such as people who use drugs, and incarcerated people.

The hierarchy of legitimacy among community members means that some people have access to opportunities, but many do not. Policy work still seems to maintain status quo notions of power and authority, and often the organizations that are already the most “successful” organizations and movements are invited to the table while others are not. It can be challenging for community organizations to establish the necessary legitimacy to be a part of the conversation and invited to decision-making spaces.

More from the MacEachen Institute

The Institute is working to create resources and policy discussions. These include briefing notes as well as panel discussions, videos, and media commentary. You can find our [research and resources](#) on our website.

MacEachen Institute briefing notes on COVID-19

- [Falling Through the Cracks: Long-Term Care and COVID-19](#)
- [The Road to Recovery for Atlantic Tourism](#)
- [Climate Adaptation in Nova Scotia: Overblown or Underwater?](#)
- [Race and Party Platforms in the Nova Scotia Election](#)
- [COVID-19: Leaders from the Health Community Identify Lessons from the First Wave and Concerns for the Second](#)
- [Lessons Learned from the First Wave or Lessons Merely Identified? Improving Nova Scotia and New Brunswick's health system for the second wave of COVID-19 and beyond](#)
- [Health Care Issues and Media Coverage Before and During the Pandemic](#)
- [The Economy and Media Coverage Before and During the Pandemic](#)
- [Social Justice Issues and Media Coverage Before and During the Pandemic](#)
- [Environmental Issues and Media Coverage Before and During the Pandemic](#)
- [Climate Risk Governance in Light of the COVID-19 Crisis](#)
- [Observations from Toronto's Tourism Recovery Post-SARS in 2003](#)
- [Foot and Mouth Disease in the U.K. in 2001: Observations for Policy-Makers and the Rural Tourism Sector in the age of COVID-19](#)
- [Labour Issues and COVID-19](#)
- [Quarantine and COVID-19](#)
- [People with Disabilities and COVID-19](#)
- [Nova Scotia Power and COVID-19](#)