POLICY DIALOGUE SUMMARY

Rights-based approaches to childhood disability

7 JUNE 2018
SHAW CENTRE, OTTAWA

The purpose of the dialogue

A policy dialogue on rights-based approaches to childhood disability was convened on 7 June 2018 at the Shaw Centre in Ottawa, with 23 decision-makers from diverse sectors, provinces, and territories in attendance.

The dialogue was organized by a team of researchers in childhood disabilities, led by the Canada Research Chair in Childhood Disabilities: Participation and Knowledge Translation, based at McGill University. The dialogue was part of the "Knowledge Translation to Policy" project funded by the Kids Brain Health Network (part of the Networks of Centres of Excellence).

The primary objective of the dialogue was to **inform decision-makers** about the available research evidence relevant to applying a human rights lens to matters related to children with disabilities in Canada. The team hoped that this sharing of information would facilitate the creation of a network of decision-makers to collaborate in future work in this area and to reframe policy issues using a rights-based approach as a strategy for action.

The secondary objective of the dialogue was to **inform researchers** about the use of different policy briefs and other types of research-driven information, as well as the utility of facilitated policy dialogues. The team anticipated that what was learned from this event would help to build a Policy Hub in Childhood Disabilities – a communication space to address questions relevant to policy, using syntheses of research evidence in the context of the current priorities of stakeholders (e.g., caregivers, youth, children, and civil society organizations).

Opening remarks

"There is nothing worse than feeling you don't belong."
– The Honourable Kirsty Duncan

The event began with an acknowledgement of the traditional territory on which the meeting venue stands. The dialogue was conducted in line with the Chatham House Rule, as explained in her preliminary remarks by Dr Shikako-Thomas, who then introduced the research team.

The Honourable Kirsty Duncan, Minister of Science and Minister of Sports and Persons with Disabilities, then gave her opening remarks. Ms Duncan acknowledged the work of the research team, especially Dr Shikako-Thomas and Simone Cavanaugh, in assembling diverse stakeholders and bringing the pressing topic of the rights of children with disabilities to the forefront. She described her ongoing engagement with the research team with respect to making childhood disability a political priority, and expressed her gratitude for their work.

The Minister also discussed her approach to promoting the rights of children with disabilities, noting that it was important to

take "a whole-of-government approach to the problem of disabilities." She explained that this involves a commitment to continue to push for accessibility legislation, for accessible housing, and for financial support for children with disabilities through the Canada Child Benefit. The Minister identified legislative issues as an area of primary concern for her.

In expressing her commitment to the rights of Canadians with disabilities, Ms Duncan acknowledged that the barriers they experience extend even to the physical inaccessibility of the House of Commons, where all citizens should be treated as equals. She also acknowledged the obstacles that people with disabilities face in trying to gain political support in meeting their challenges, one being the tendency for political representatives to simply shift responsibility to another jurisdiction, such as the federal, municipal, or provincial/territorial level of government. She noted that what people want is for their problems to be resolved, not to be told which tier of government is responsible.

"I can promise you, you have a champion," she said, drawing attention to the fact that although a significant proportion – 14% – of Canadians self-identify as having a disability, many people with disabilities still feel excluded from full participation in society.

Presentation of the research

Dr Keiko Shikako-Thomas from the McGill University team described the process through which the dialogue was convened, and the research material that was prepared. She

provided an overview of the steps involved in the literature review conducted by the research team: systematically searching the research literature in five different research databases, identifying articles that addressed rights-based approaches related to childhood disabilities, mapping the concepts extracted from these articles, and transforming the content into questions related to the articles of the United Nations Convention on the Rights of Persons with Disabilities. These questions were sent to disabled persons organizations and to parents of children with disabilities across Canada for their reflection and input.

Dr Jonathan Lai from the research team described the process through which the research team sought to connect the research findings with actual experience by including the voices of grassroots organization and youth, including the findings of a photo elicitation process through which young people's

perceptions of the relevance of the findings were explored. This information was primarily quantitative.

The discussion then paused to give participants the opportunity to provide feedback on the presentation of qualitative research findings through a brief questionnaire.

Key discussion points

The next part of the policy dialogue engaged participants in a discussion of possibilities for the practical application of the research findings. Using a "Think–Pair–Share" approach, participants discussed in pairs their impressions about how the findings presented could be translated into concrete policy actions. These one-on-one exchanges were brought to a close with an invitation for participants to share with the whole group what they had discussed.

One of the discussion points conveyed to the group was that some participants were already making use of rights-based approaches in their work. However, barriers to the integration of rights-based approaches were also pointed out; these included the lack of good data on children with disabilities. Another point of discussion was the need for flexibility in addressing the diverse needs of families, as well as the need to take a proactive approach to disability rights with the timely provision of services that fit families' actual needs, and by "getting the word out" about the existence of these services. Instead, families are left to search out information and services for themselves.

A participant who had worked for more than twenty-five years in the area of rights and disabilities drew the group's attention back to the research process, and to the fact that the organizations that responded to the survey face ongoing structural challenges in meeting the needs of people with disabilities. For example, limited financial resources and a lack of literacy in "rights language" can pose a challenge to efforts to truly represent the needs of the population.

The research group clarified the process by which the list of organizations who contributed to the project was compiled, as well as the relative proportions of advocacy groups and service-providing organizations. Consideration was also given to families who are not connected to organizations, and those who, because of geographic factors, lack of awareness, or social isolation are not well integrated into the system and are therefore often misrepresented or under-represented in any consultation process. The emphasis of the project was on gaining multi-stakeholder perspectives on actionable solutions, and on discussing implementation considerations in policy-making at different levels.

One primary finding from the research team's review was the need to support families and children across the lifespan, in part to reduce the caregiver burden, which often falls primarily on women. Another challenge identified was the perception that leisure activities are a luxury, rather than an important determinant of health outcomes; this observation elicited affirmative nods from many participants.

Dr Shikako-Thomas then shared the voices of the youth who participated in the project and conveyed their primary concerns, which centred on the inaccessibility of physical spaces and amenities such as transport. To illustrate

this concern she shared, with permission, the following poem written by a participant.

> ### Frustrated
>
> *Niko Yannakis*
>
> I get frustrated in my wheelchair
> when I can't get everywhere.
>
> When an elevator is out of commission
> it spoils my shopping mission.
>
> I sometimes need my Uncle Mike
> to get me into a store.
>
> He lifts my wheelchair up
> so I can shop some more.
>
> I get frustrated in my wheelchair
> when I can't get everywhere.

At this point, participants were again invited to provide feedback on the presentation through a questionnaire.

Some of the research team's research programs were shared with the participants. These included the 12 projects in the CHILD-BRIGHT Strategy for Patient-Oriented Research (SPOR) program, which focus on brain-based disabilities, and several projects on brain development being undertaken by the Kids Brain Health Network (part of the Networks of Centres of Excellence of Canada).

Another member of the research team, Dr Mayada Elsabbagh, then briefly presented the work of the Transforming Autism Care Consortium (TACC). She discussed the importance of moving into translational research – research with clear, real-world applications that can make an important impact through its integration into health services.

"If we don't work actively with policy-makers and decision-makers, we will never make any progress," she said. She emphasized that, in working collaboratively with systems players, relationship-building is key. Establishing relationships with policy-makers at various levels will allow those active in research to identify ways to be useful in informing policy decisions. A discussion on the specific topic of autism ensued after lunch.

Selection of priorities from research

The five main themes that the research team presented as emerging from their review are shown in the textbox below. Participants were invited to use the stickers in their program workbook to vote on what they would consider

**Main themes selected
from the research review**

1 There is a need to **identify and measure the barriers to full inclusion** to develop policies, programs, and interventions.

2 There is a lack of opportunities to **participate equally in public life**.

3 There is a lack of ownership and **active engagement in decision-making** related to children and youth with disabilities.

4 Strategies and **policies to promote participation in leisure activities** are lacking.

5 The **lack of integrated and adequate services** places an economic, psychological, and medical **burden of care** on families (especially on women).

actionable priorities from these five themes, based on their potential to be integrated into their current policy portfolios. They were asked to consider which of these priorities would have the most impact if implemented, which would be the most feasible to implement, and which would be the most important to their constituents.

Participants were then asked to break out into groups, according to the priority they considered most feasible to put into action, with the objective of discussing real implementation considerations. This resulted in four discussion groups, each with two to seven members.

Identification of actionable priorities

After a break, participants were assigned to groups to work together on a "minimum viable plan." The intention was to consider real implementation challenges, to capitalize on opportunities for sharing and collaboration that could arise from events such as this policy dialogue, and to reflect on constraints in their work environment. Participants were encouraged to consider the costs, risks, and constraints they might face in attempting to implement these approaches, and who might be affected by implementation.

Some of the themes that emerged from the group discussions are described below.

In Group 1, participants had chosen the **identification and measurement of barriers to inclusion** as a priority. Their "concrete area" of focus within this priority was "data collection." They noted that the last Canadian Participation and Activity Limitation Survey was conducted in 2006, and that Canada does not have recent data to support the quantification of barriers. They addressed the need to use international guidelines to set benchmarks and standards for the type of data collected, as well as for the services and support offered as a consequence. While acknowledging that international guidelines may not lend themselves to direct translation in each context, then can serve as an incentive for data collection. The group also discussed the need to increase awareness among higher levels of government about the importance of inclusion, which would create a trickle-down effect at the lower levels of power. Another priority in improving inclusion would be to promote intersections between the federal and provincial levels. On this issue, international guidelines were mentioned as a means to standardize the definition of disabilities and the

benefits associated with these definitions across provinces.

Group 2 discussed the use of **international human rights guidelines as a benchmark for the evaluation of Canadian policies**. The idea of guideline use was presented as a means of gaining precision in the definition of parameters. Some considerations were raised in this regard, one being the difficulty of establishing precise parameters for jurisdictions as diverse as the federal level and the over 700 First Nations who will be independently administering their services. Another participant discussed the need for collaboration across provinces and territories, as well as the need for both bottom-up advocacy and top-down leadership to meet in order to effect change. Gender-based analysis was brought up as a prominent issue at the federal level: one participant mentioned that mandatory requirements for gender reporting, with a bureaucratic mechanism implemented at the federal government level, ensures that this consideration is now explicitly included rather than being diluted in broader statistical analyses. This was mentioned as an example of what can be done to make disabilities also an explicit consideration at all decision-making levels.

Group 3 echoed the need for a gender-based approach, noting that the disaggregation of data and the use of a standard process and measurement system for evaluation would be useful in drawing attention to the needs of people with disabilities. Participants in this group echoed the concern raised by Group 2 that nuances are lost when aggregated data are considered at a high level. Group 3 group then proceeded to discuss their selected priority: **facilitating and supporting professional services**. In line with this aim, they discussed the possibility of better connecting federal and provincial governments as well as responding

to needs for community-based professional supports. Community services often face challenges related to recruitment and retention. For such groups, it is also critical to have a support and information network or someone from the government to connect them with appropriate advisors on existing evidence, services, and supports that extend beyond short briefings and summaries.

Group 4 focused on **the need to engage youth and children in self-advocacy**. They discussed the potential to harness already existing public awareness activities, such as National Access Awareness Week or Human Rights Day. Such days could include a theme that highlights children with disabilities. Within the classroom, a curriculum could be created for children, perhaps focusing on accessibility and barriers to accessibility – and not necessarily specifically on disability. One participant noted that the theme of accessibility would be a helpful entry point to raise awareness, since accessibility is a commonly shared concern. The group mentioned school-based recycling awareness campaigns as a good example of how children can be empowered to lead advocacy efforts: by advocating recycling to their parents, children have helped to change the culture around recycling. Suggestions included school-based

campaigns with books in which the hero is a child with a disability, and engaging advocacy organizations in the long-term planning of public awareness campaigns. Advocacy efforts would also involve collaborations among government, non-governmental organizations, and teachers. In this regard, Dr Shikako-Thomas advocated that researchers also be considered as part of this collaborative unit.

A participant also added that sports-based organizations would be a welcome addition to this collaboration, given that people with disabilities often find their voice through sports.

The discussion on the need to empower and actively engage communities in decision-making processes as a "positive rights-based approach" was counter-balanced by the discussion on court cases that can often fuel "knee-jerk" reactions that then lead to entrenched policies, in a negative rights-based approach. It was also highlighted that the process of involving communities would need to include the perspectives of children and their families. One participant gave an example from a territory, where they wanted to work to ensure that the voice of Indigenous communities was central. This discussion point raised the need to ensure that the process is inclusive and that all voices are represented.

After the four groups had reported on their discussions, Dr Shikako-Thomas invited the entire group to consider small, concrete steps that could be taken to help implement some of the ideas discussed. She also asked how the research team could help by contributing research that is applicable and meaningful to their different spheres of political influence.

Participants were asked to fill out a questionnaire, based on the Theory of Planned Behavior, about what they intended to do, not just with the research information provided, but also in light of the exchanges experienced throughout the day. The research team also noted that, to facilitate collaboration, contact information would be shared, with consent, among those present.

Final participant reflections and key takeaways

Four key areas brought up by participants in the final reflections are described below

1 Connection

Participants noted that they appreciated the opportunity to connect with players at various jurisdictional levels. For example, a participant from the federal government remarked that the dialogue provided a better understanding of issues at the provincial level, while offering an opportunity to think about their own constituents and how they might be affected by issues pertaining to children with disabilities. Meanwhile, participants at the provincial level voiced appreciation for the opportunity to meet people at the federal policy level. This multi-level and multi-sectoral perspective allowed for a panoramic view of challenges

as well as highlighting parallels in issues and approaches, which is essential in promoting the rights of children with disabilities. Many participants valued not only the opportunity to share their own experiences and concerns, but also appreciated the similarities highlighted by various participants. Overall, the dialogue was seen as a valuable opportunity to connect and to share successes, experiences, and ongoing challenges. Participants expressed interest in continuing to build on those connections after the dialogue.

2 A rare opportunity to access research evidence as a resource for reflection, improvement and action

Some participants noted that the dialogue and the associated brief gave them a unique opportunity to access the research evidence on the topic of the rights of children with disabilities, and to think about their roles in policy and programming development in relation to the research evidence presented. They also reflected on mechanisms and best practices for incorporating academic research into their work. The brief also gave them a resource to (1) support their assessment of their own actions and approaches, (2) reflect on methods to incorporate rights-based practices into their current practice, (3) validate their current practice, and (4) inform their work with their team to improve lived experience and outcomes for children with disabilities. Participants shared their understanding of the role of fostering a holistic and collaborative approach in advancing the rights of children with disabilities.

3 An opportunity to hear the voices of children with disabilities

Participants appreciated the inclusion of input from children and youth with disabilities

in the evidence provided. The observation of the value that children and their parents attributed to international guidelines also sparked a discussion on the importance of these guidelines at the community level for leveraging awareness of issues affecting children with disabilities and helping to bring a disability lens to bear on discussions about social policy. Participants noted that Canada's leadership role in the United Nations Convention on the Rights of Persons with Disabilities and our influence through the Canadian Human Rights Commission had made the United Nations instruments and guidelines very influential locally for parents and organizations. Participants also noted that champions with disabilities themselves would be the ones to carry the issues forward, and that youth involvement in the process is therefore crucial.

4 The need for more data

Participants noted that data with a specific focus on children with disabilities were necessary to inform the creation of better policies and resources for children with disabilities. Attention was placed on the Canadian Survey on Disability, which does not specifically capture children, and more broadly on the need to capture child health issues with respect to the challenges that children with disabilities and their families face. Population-based data were seen as a key resource for increasing awareness of unresolved issues and policy gaps.
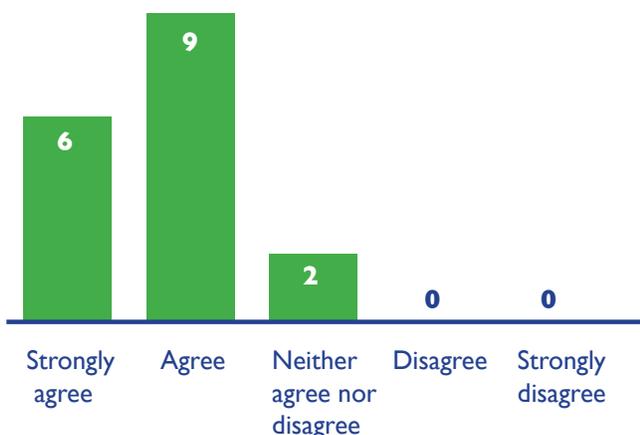
Participant feedback
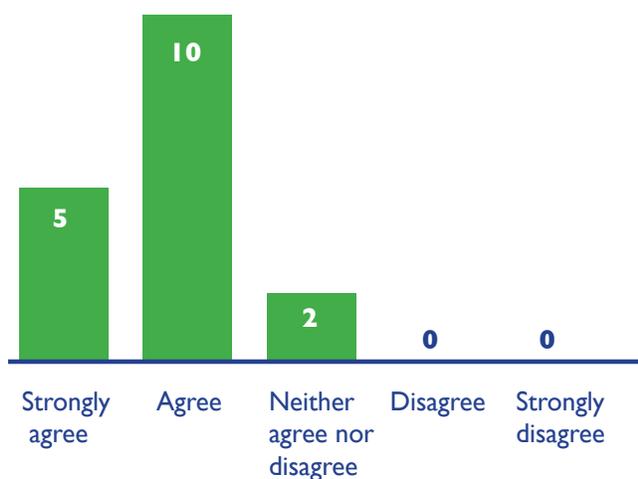
Participants filled out questionnaires about the event at the end of the day. The graphs below illustrate (1) overall satisfaction with the event and (2) whether they thought it was a good use of time. There were 17 respondents to these questions (out of 22 questionnaires completed).

As a result of my participation in this activity, I am better informed about rights-based approaches to childhood disabilities

6	9	2	0	0
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

This activity was a good use of my time

5	10	2	0	0
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

In closing, Dr Shikako-Thomas thanked all participants for attending the policy dialogue and expressed the research team's appreciation for the opportunity to hear from stakeholders at all government levels. The team reiterated the need for research to move beyond the academic realm in order to influence policy. The team then presented the idea of the Policy Hub in Childhood Disabilities as an open channel for discourse and networking

around issues of childhood disability. The Policy Hub will be developed by researchers and trainees from CHILD-BRIGHT and the Kids Brain Health Network, and will involve trainees and other stakeholder groups to facilitate these exchanges, synthesize research studies, and produce policy briefs and other relevant information for decision-makers.

Finally, participants were informed of the opportunity to use the research team as a resource for finding relevant research (such by requesting rapid reviews), in appraising and collecting the best research evidence to inform action, and in acting as networking resource to facilitate collaborations.

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Reference

For a summary of the research evidence presented at the policy dialogue, see:
Lai J. Rights-based approaches for children with disabilities in Canada. Policy brief. Canada Research Chair in Childhood Disabilities. Spring 2018. Available from: www.childhooddisability.ca/wp-content/uploads/2018/07/PolicyBrief_Spring2018.pdf

Competing interests

The authors declare that they have no professional or commercial interests relevant to the dialogue summary.

The views expressed in the evidence brief are strictly those of the authors.

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