

RIGHTS-BASED APPROACHES FOR CHILDREN WITH DISABILITIES IN CANADA

The Issue

Canadian children with disabilities are particularly vulnerable to discrimination in accessing their rights, as they are in the intersection between the CRC and CRPD.

The **Convention on the Rights of the Child (CRC)** was the first human rights treaty to include disability as grounds for protection from discrimination. The rights enshrined in the CRC are categorized by the following four guiding principles: non-discrimination; best interest of the child; the right to life, survival and development; and the right to participate. However, while providing a dedicated and comprehensive framework for the rights of children, the CRC does not address the significant barriers that children with disabilities experience in realising those rights.

The more recent **Convention on the Rights of Persons with Disabilities (CRPD)**, in contrast, demands a fundamentally different approach to disability, centered on the social model of disability and the notion of inclusion and expands on the CRC for this population. However, the implementation of the CRPD has been grossly underwhelming in Canada, failing to create a fully inclusive environment for children with disabilities. This was emphasized in the UN's 2017 *Concluding Observations on the Initial Report of Canada*:

"The Committee is concerned about the absence of formal, recorded consultations on comprehensive plans for the implementation of the Convention, and about the absence of information on mechanisms to foster the leadership and participation of [...] children with disabilities in consultations. The Committee notes with concern that the Government of Canada has not collected data on children with disabilities since 2006. [...] It is further concerned about the lack of criteria established for applying the principle of the best interests of the child in actions concerning children with disabilities."

The Opportunity

In Canada, adequate legislation protecting the rights of individuals with disabilities is lacking, as are monitoring and enforcement mechanisms.

Often as a last resort (for individuals, families, groups or organizations), litigation has been used as a tool to affirm the rights of children with disabilities and pursue proper application and enforcement.

With federal accessibility legislation on the horizon, it is imperative that policy makers take action on all fronts to empower children with disabilities and create a more inclusive Canada for everyone.

What this brief is about?

This brief aims at informing decision-making about children with disabilities in Canada. We identify actionable points based on research evidence and stakeholder feedback using rights-based approaches.

What we did?

We searched the academic research literature to identify issues and solutions on how children with disabilities equally accessing their rights. We surveyed 107 grassroots community organizations, 33 parents and 5 youth to validate these findings and identify gaps.

Survey of Parents and Grassroots Organizations on the Evidence

Participants were asked about 6 issues related to the themes of inclusion, participation and family support.

The relevance of the issue to the participant by stakeholder type was rated (shown on the left). If an issue was important to the participant, potential solutions from the literature were presented. The ratings of the top solutions by level of importance are presented below on the right.

Data was collected from:

48 grassroots organizations represent disability groups for children with disabilities across Canada at federal and provincial levels (25% were federal organizations, 32% from the Western provinces, 37% from Central Canada, and 7% from the Atlantic provinces.)

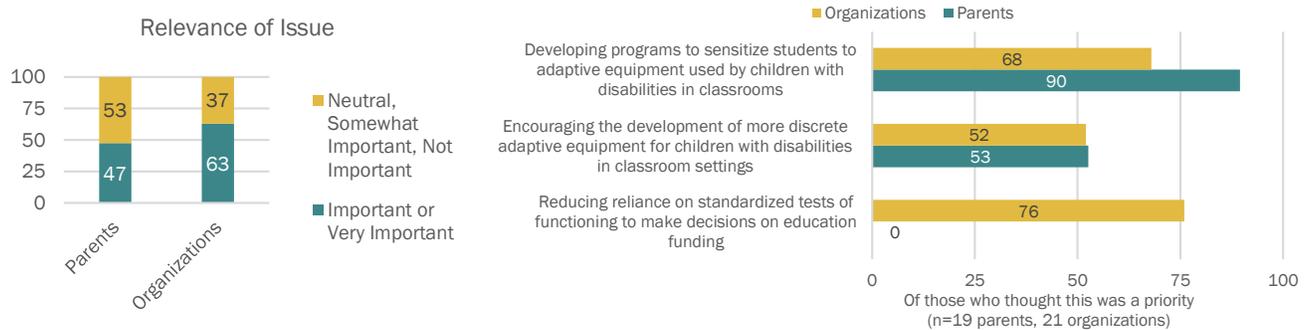
35 parents with children ranging from 3-27 years old, with a mean of 12.3 years old. Children had conditions ranging from brain injury at birth, developmental delay, autism, cerebral palsy, FASD, Down's Syndrome and other genetic syndromes, epilepsy, and speech and language conditions.

Results

1 We need to identify and measure the physical, social, cultural, and economic barriers to full inclusion in order to develop policies, programs and interventions for children with disabilities



2 Children with disabilities should be included in educational settings without discrimination from classmates and teacher



3 Children with disabilities lack opportunities to participate equally in public life and in activities that are crucial for them to reach their full potential (e.g. leisure, community life, school activities, decision making)



4 There is a lack of ownership and active engagement of children and youth with disabilities in decision making related to them



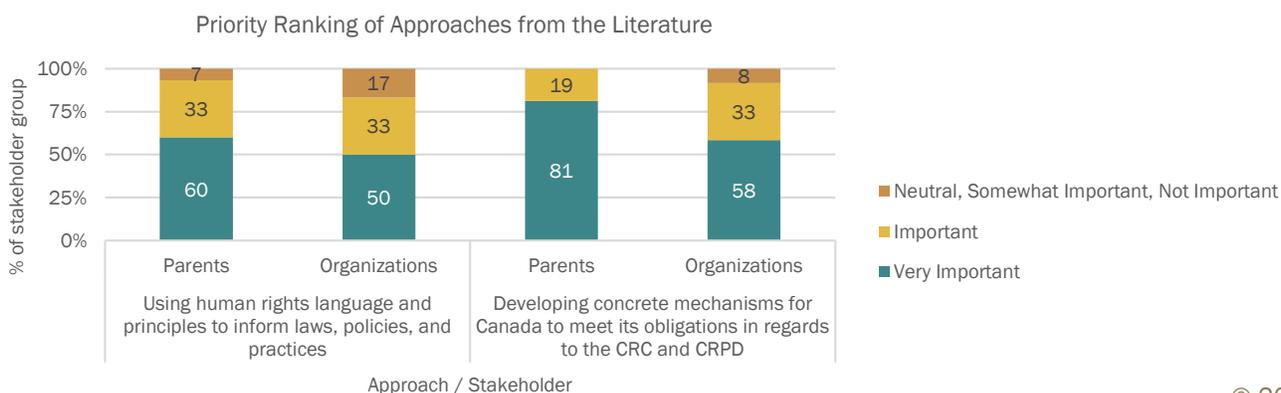
5 Strategies and policies to promote participation in leisure activities (e.g. sports and other recreational activities) for children with disabilities are lacking



6 There is a lack of integrated and adequate social, health, and educational services for children with disabilities, placing economic, psychological and medical burden of care from the state to the family (especially on women)



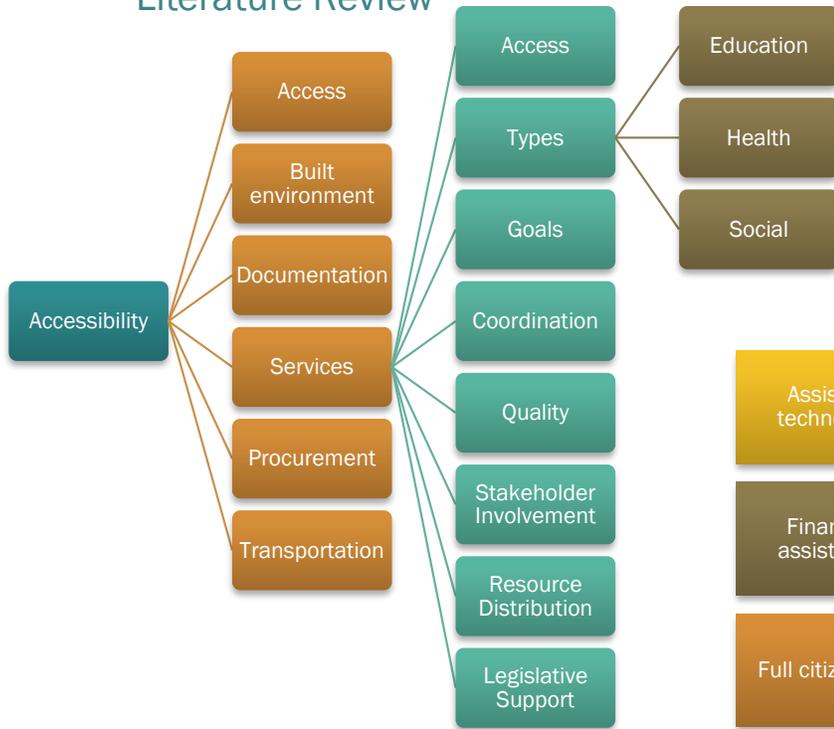
How stakeholders ranked using 2 rights-based approaches from the research literature



Actionable Areas Identified in the Research Literature

112 articles discussing rights-based approaches for children with disabilities were analyzed

Example of Concept Map from Literature Review



Actionable Topics Identified



Solutions were grouped into 5 categories



Approaches from the Research Literature

112 articles discussing rights-based approaches for children with disabilities were analyzed.

1 Youth and parent agency: awareness and engagement

- Support parenting approaches that teach the child self-agency and the importance of working⁷
- Empower self-advocacy⁴⁰
- Implement a nationwide education campaign be launched to sensitize the population at large (UN Committee on the Rights of the Child 1995, Section D-19)
- Increase culturally relevant services to families of those living with disabilities³⁹

2 Individual Supports and Reasonable Accommodation

- Mandate public reasonable accommodations to ensure more affirmative equality²⁵
- Provide sign-language interpreters, physically accessible courts, and access to lawyers in rural communities²¹
- Design a comprehensive support that includes
 - 1) consultations with persons with disabilities, awareness-raising measures, accessibility standards, income support and tax measures, the Canada Social Transfer, support for victims of crime, and the Employment Equity Act²⁹ as well as welfare payment for caregivers³
 - 2) right of adequate income through a comprehensive disability program, health-care reform, employment equity and accessible transportation system³⁵
- Create an Accessibility Fund where violation fines to accessibility building codes would to ensure the full accessibility of public buildings³³
- Change permanent unemployability criteria for financial assistance to programs that aim at increasing life and work skills⁶

3 Promoting active citizenship by universal design

- Planning and monitoring infrastructure design to facilitate universal design principles^{4, 36} and accountability mechanisms.^{36, 37} Specific areas include public transportation,¹⁰ urban decision making.⁴²
- Implement a social model of disability horizontally in the policy-making process.³⁰
- Refer to South Africa leads as a role model for including disability social and political rights into its constitution.²⁴

4 Person- and family-centered approaches

- Encourage services to be family-centred, and beyond family involvement heavily reliant on moms¹⁷
- Encourage caregivers to actively participate in decision and policy-making process^{12, 23} and service evaluation.^{13, 43}
- Invest in effective transition planning to maximizing post-school outcomes.³⁴
- Clearly define who is a child with disabilities for proper service access.¹⁸

5 Service provider capacity building and coordination

- Create databases to share community information¹¹, interagency hub¹³ and families' network²⁸; for example, a program called "Publicity Plan" facilitates access to up to date information about policies and programs for families and providers.³⁴
- Evaluate care with an axis focusing on information sharing modalities and families perceptions of access to information.¹⁷
- Integrate NGOs across disabilities to strengthen advocacy and impact of programs²⁸
- Ensure the horizontal implementation of programs following inter-departmental policies addressing children with disabilities through cross-departmental coordination and accountability.³⁷
- Training opportunities in information-seeking skills⁴⁴, advocacy training³⁸, education on their rights, as well as about accessing the legal system to assert⁴⁵
- Promote experience-sharing amongst multidisciplinary professionals^{5, 23}
- Invest in sustained learning for providers to have up-to-date best practices, promote skills related to care provision such as flexibility and self-care and encourage information dissemination⁵

References

1. Al-Heresh, R. & Wendy, W. (2003). Community-based rehabilitation in Jordan: challenges to achieving occupational justice. *Disability & Rehabilitation*, 35(21), 1848-1852.
2. Badia, M., Orgaz, B. M., Verdugo, M. A., Ullán, A. M., & Martínez, M. M. (2011). Personal factors and perceived barriers to participation in leisure activities for young and adults with developmental disabilities. *Research in Developmental Disabilities*, 32(6), 2055-2063.
3. Baker, D.L. (2008). Issue definition in rights-based policy focused on the experiences of individuals with disabilities: An examination of Canadian parliamentary discourse. *Disability & Society*, 23(6), 571-583.
4. Baker, K. & Donnelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society*, 16(1), 71-85.
5. Bakare, M. O., et al. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics* 9: 12.
6. Beatty, H. (1999). Ontario Disability Support Program: Policy and Implementation. *Journal of Law and Social Policy*, 14, 1-68.
7. Berrey, E. & Nielsen, L.B. (2007). Rights of Inclusion: Integrating Identity at the Bottom of the Dispute Pyramid. *Law & Social Inquiry*, 32(1), 233-260.
8. Bérubé, M. (2009). Citizenship and disability. *Disability: The Social, Political, and Ethical Debate*, 205-213.
9. Bickenbach, J.E. (2014). Universally designed social policy: When disability disappears? *Disability & Rehabilitation*, 36(16), 1320-1327.
10. Chadha, E. (2005). Running on Empty: The Not So Special Status of Paratransit Services in Ontario. *Windsor Rev. Legal & Soc. Issues*, 20, 1-40.
11. Cigno, K., & Gore, J. (1999). A seamless service: meeting the needs of children with disabilities through a multi-agency approach. *Child and Family Social Work*, 4, 325-336.
12. Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation*, 24(10), 542-549.
13. Dowling, M. & Dolan, L. (2001). Families with Children with Disabilities – Inequalities and the Social Model. *Disability & Society*, 16(1), 21-35.
14. Eklund, K., Sonn, U., & Dahlin-Ivanoff, S. (2004). Long-term evaluation of a health education programme for elderly persons with visual impairment. A randomized study. *Disability & Rehabilitation*, 26(7), 401-409.
15. Engel, D. M. & Munger, F. W. (1996). "Rights, Remembrance, and the Reconciliation of Difference." *Law & Society Review*, 30(1): 7-53.
16. Fisher, K. R., et al. (2012). Barriers to the Supply of Non-Government Disability Services in China. *Journal of Social Policy*, 41(1), 161-182.
17. Fordham L., Gibson, F., & Bowes, J. (2012). Information and professional support: key factors in the provision of family-centred early childhood intervention services. *Child: care, health and development*, 38(5), 647-653.
18. Goodley, D., & Runswick-Cole, K. (2011). Problematizing policy: conceptions of 'child', 'disabled' and 'parents' in social policy in England. *International Journal of Inclusive Education*, 15(1), 71-85.
19. Grenwelge, C. & Zhang, D. (2013). The effects of the Texas Youth Leadership Forum Summer Training on the self-advocacy abilities of high school students with disabilities. *Journal of Disability Policy Studies*, 24(3), 158-169.
20. Groce, N. E., et al. (2014). Inheritance, poverty, and disability. *Disability & Society*, 29(10), 1554-1568.
21. Hill, A. J. (2012). Are There Differences in Leadership Styles at Local, State and National/federal Levels Among Advocates for People with Disabilities? (Doctoral dissertation, Our Lady of the Lake University).
22. Hunt, P. and J. Mesquita (2006). Mental Disabilities and the Human Right to the Highest Attainable Standard of Health. *Human Rights Quarterly*, 28(2), 332-356.
23. Heap, M., et al. (2009). 'We've moved away from disability as a health issue, it's a human rights issue: reflecting on 10 years of the right to equality in South Africa. *Disability & Society*, 24(7), 857-868.
24. Heyer, K. (2002). The ADA on the road: Disability rights in Germany. *Law & Social Inquiry*, 27, 723-762.
25. Heyer, K. (2007). A disability lens on sociological research: Reading rights of inclusion from a disability studies perspective. *Law & Social Inquiry*, 32(1), 261-293.
26. Lee, L., Arthur, A., & Avis, M. (2007). Evaluating a community-based walking intervention for hypertensive older people in Taiwan: A randomized controlled trial. *Preventive Medicine*, 44(2), 160-166.
27. Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of pediatric health care*, 20(4), 245-252.
28. MacLachlan, M.M. & Mannan, H. (2014). The world report on disability and its implications for rehabilitation psychology. *Rehabilitation Psychology*, 59(2), 117-124.
29. Malhotra, R. H. & Robin F. (2011). United Nations Convention of the Rights of Persons with Disabilities and its Implications for the Equality Rights of Canadians with Disabilities: The Case of Education. *Windsor Y.B. Access Just.*, 29, 73-106.
30. Mosoff, J. (1998). Excessive Demand on the Canadian Conscience: Disability, Family, and Immigration. *Man. L.J.*, 26, 149-180.
31. Munro, E. et al. (2011). The contribution of the United Nations Convention on the Rights of the Child to understanding and promoting the interests of young people making the transition from care to adulthood. *Children & Youth Services Review*, 33(12), 2417-2423.
32. Patterson, L. (2012). Points of access: Rehabilitation centers, summer camps, and student life in the making of disability activism, 1960-1973. *Journal of Social History*, 46(2), 473-499.
33. Philipps, S.D. (2009). Civil society and disability rights in Post-Soviet Ukraine: NGOs and prospects for change. *Indiana Journal of Global Legal Studies*, 16(1), 275-291.
34. Poon-McBrayer, K.F. (2012). Bridging policy-practice gap: Protecting rights of youth with learning disabilities in Hong Kong. *Children and Youth Services Review*, 34(9), 1909-1914.
35. Porter, B. (2005). Twenty years of equality rights: Reclaiming expectations. *Windsor Y.B. Access Just.*, 23, 145-192.
36. Prince, M.J. (2002). The governance of children with disabilities and their families: Charting public-sector regime in Canada. *Canadian Public Administration*, 45, 389-409.
37. Prince, M.J. (2004). Canadian disability policy: Still a hit-and-miss affair. *Canadian Journal of Sociology*, 29(1), 59-82.
38. Rosenthal, E. et al. (1999). Implementing the right to community integration for children with disabilities in Russia: A human rights framework for international action. *Health and Human Rights*, 4(1), 82-113.
39. Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education*, 30(3), 144-149.
40. Sabatello, M. (2005). Reviewed work: The human rights of persons with intellectual disabilities: Different by equal by Stanley S. Herr. *Human Rights quarterly*, 27(2), 737-749.
41. Shikako-Thomas, K. & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: From policy to play. *Disability & Society*, 30, 1-20.
42. Stephens, C.C. et al. (2012). Urban inequities; Urban rights: A conceptual analysis and review of impacts on children and policies to address them. *Journal of Urban health*, 89(3), 464-485.
43. Thyen, U., Sperner, J., Morfeld, M., Meyer, C., & Ravens-Sieberer, U. (2003). Unmet health care needs and impact on families with children with disabilities in Germany. *Ambulatory Pediatrics*, 3(2), 74-81.
44. Tsai, E. H. L., & Fung, L. (2009). Parents' experiences and decisions on inclusive sport participation of their children with intellectual disabilities. *Adapted Physical Activity Quarterly*, 26(2), 151-171.
45. Vilchinsky, N. & Findler, L. (2004). Attitudes toward Israel's equal rights for people with disabilities law: A multiperspective approach. *Rehabilitation Psychology*, 49(4), 309-316.
46. Weisz, V. & Tomkins, A. J. (1996). The right to a family environment for children with disabilities. *American Psychologist*, 51, 1239-1245.

about us

The PARTICipation and Knowledge Translation - PAR KT Lab is based at McGill University and the Center for Interdisciplinary Research in Rehabilitation of the Greater Montreal (CRIR) and is led by the Canada Research Chair in Childhood Disability: Participation and Knowledge Translation that does research aimed at improving the health of Canadian children with disabilities by engaging different stakeholders and connecting academic research and policy.

This brief was created by Jonathan Lai (PhD), CIHR Health System Impact Fellow, McGill University.

contact information

Keiko Shikako-Thomas, PhD, OT,
Canada Research Chair in
Childhood Disability: Participation
and Knowledge Translation
keiko.thomas@mcgill.ca

This project was funded by



with infrastructure support from



RIGHTS-BASED APPROACHES FOR CHILDREN WITH DISABILITIES IN CANADA

The Issue

Canadian children with disabilities are particularly vulnerable to discrimination in accessing their rights, as they are in the intersection between the CRC and CRPD.

The **Convention on the Rights of the Child (CRC)** was the first human rights treaty to include disability as grounds for protection from discrimination. The rights enshrined in the CRC are categorized by the following four guiding principles: non-discrimination; best interest of the child; the right to life, survival and development; and the right to participate. However, while providing a dedicated and comprehensive framework for the rights of children, the CRC does not address the significant barriers that children with disabilities experience in realising those rights.

The more recent **Convention on the Rights of Persons with Disabilities (CRPD)**, in contrast, demands a fundamentally different approach to disability, centered on the social model of disability and the notion of inclusion and expands on the CRC for this population. However, the implementation of the CRPD has been grossly underwhelming in Canada, failing to create a fully inclusive environment for children with disabilities. This was emphasized in the UN's 2017 *Concluding Observations on the Initial Report of Canada*:

"The Committee is concerned about the absence of formal, recorded consultations on comprehensive plans for the implementation of the Convention, and about the absence of information on mechanisms to foster the leadership and participation of [...] children with disabilities in consultations. The Committee notes with concern that the Government of Canada has not collected data on children with disabilities since 2006. [...] It is further concerned about the lack of criteria established for applying the principle of the best interests of the child in actions concerning children with disabilities."

The Opportunity

In Canada, adequate legislation protecting the rights of individuals with disabilities is lacking, as are monitoring and enforcement mechanisms.

Often as a last resort (for individuals, families, groups or organizations), litigation has been used as a tool to affirm the rights of children with disabilities and pursue proper application and enforcement.

With federal accessibility legislation on the horizon, it is imperative that policy makers take action on all fronts to empower children with disabilities and create a more inclusive Canada for everyone.

What this brief is about?

This brief aims at informing decision-making about children with disabilities in Canada. We identify actionable points based on research evidence and stakeholder feedback using rights-based approaches.

What we did?

We searched the academic research literature to identify issues and solutions on how children with disabilities equally accessing their rights. We surveyed 107 grassroots community organizations, 33 parents and 5 youth to validate these findings and identify gaps.

Voices of Parents and Grassroots Organizations on the Evidence

Participants endorsed and commented on solutions from the research literature. Below are quotes from parents and grassroots organizations representing disability groups for children with disabilities across Canada. Identifying information was removed to protect the identity of participants.

Social Inclusion

All the organizations believed that this issue was relevant to their work; in contrast, about half (54%) of parents said that this issue was relevant to their concerns.

The top solutions endorsed on this topic were:

- Using international human rights guidelines to evaluate Canadian policies
- Using international human rights guidelines to guide standards of services
- Measuring inclusion into communities as an indicator of success for interventions

Example of importance

"I have the expectation that my children, like all children, [would] be able to experience their world through whatever means they can accept in order for them to become the best versions of themselves. It would be unfair of me and others to make decisions for their outcome based on what they think is needed." - parent

"Full inclusion is [...] important because my child is a human being and deserves to be included." - parent

"My son and our family need to be connected and supported in order to ensure he continues to grow into a well-adjusted adult, and that we are the best parents we can be for him." - parent

"It is important to us that our child have community options for socialization and an ability to network, make friends and be part of society." - parent

Comments on Solutions

"We believe the convention is a great guide for inclusion- in both creating and evaluating inclusion policies." - organization

Caregiver burden

The majority (83%) of organizations said that this issue was relevant to their work; while all the parents said that this issue was relevant.

The top solutions endorsed on this topic were:

- Encouraging family involvement with providers in decision making
- Emphasizing an integrated approach across services that encourages greater coordination
- Facilitating and supporting community-based professional support services

Example of importance

"This is my case, I am not working because [it] is very hard for me to be taking care of her 24 hours [a day...]. Sometimes I'm so tired, I'm upset, I'm angry because I'm tired. Medication, activity all the day, all the caring for her - mommy is friend, doctor, and I'm a human, it's not possible to have 24h of this during the whole life, this is impossible- life is very complicated." - parent

"Sometimes, social inclusion by itself is not the best indicator of success. The quality of the social interactions is critical, and ensuring that social needs are identified and targeted for thoughtful intervention, building a community and team with the child and family, is important." - organization

"You have to measure the full citizenship - what are the markers of full citizenship, and include that in policy." - parent

"Just because policy has been adequate in past does not mean it is keeping up with the societal changes and expectations... There is a disconnect between what has worked in past, what is available now and what could be made accessible." - parent

"While all these measures will be very useful, maybe try to also account for individuality, personality, variation among children." - parent

Other Key Solutions

"Talking to the families and individuals with special needs in order to find out what is needed from their perspective." - parent

Comment on Solutions

"I think its really great in theory but much harder in practice. In some respects, I think families and parents do have voices with health care providers 1-on-1. But how you generalize that to actually have impact on service and on research and on health-providers. How you do it - system isn't really set up for this." - parent

Inclusive Education

Two-thirds of organizations said that this issue was relevant to their work; while about half (47%) of parents said that this issue was relevant to their concerns.

The top solutions endorsed on this topic were:

- Reducing reliance on standardized tests of functioning to make decisions on education funding
- Encouraging the development of more discrete adaptive equipment for children with disabilities in classroom settings
- Developing programs to sensitize students to adaptive equipment used by children with disabilities in the classroom

Example of importance

"Many technology aids can benefit all students - for example providing tablets for all students helps all students learn and ensures students with disabilities do not feel singled out. The more we can build UDL into classrooms and teaching, the more all students can access the supports they need. Some aids do need to be targeted of course, but many can be integrated into teaching in a way that does not single out those with disabilities." - organization

"If we have integrated classrooms from the beginning of children's education, pre-k etc., I believe that it would become a normal/accepted practice for children and not even questioned. Look back to racial integration, [it becomes a] societal norm. We have constructed it this way." - parent

Comments on Solutions

"Financial constraints are not a barrier; the largest barrier is attitude and expectation. Inclusive education is successful in many communities around the world where no financial support is available. Barriers are different in implementation around the world." - organization

Standardized testing doesn't seem like a solution for identifying important problems like behavioral issues, social engagement and things like sensory processing sensitivities.

Those types of indicators (standardized testing) are often too narrow to help identify the need for help." - parent

"I don't know if standardized tests are a good way to go, but I don't know if there is a better way - do we want equity or equality? how do we start?" - parent

"In my experience exposure decreases discrimination if teachers model acceptance and focus on strengths rather than deficits." - parent

Other Key Solutions

"Helping schools identify barriers and providing funding, advice and assistance to help overcome those barriers. Providing teachers with training on inclusive teaching practices such as UDL, sharing examples of best practice including use of technology and aids, tips on inclusive techniques etc. Mandating disability education as part of curriculum, so all students learn about people with disabilities, access and inclusion. Providing access to positive role models for students with disabilities. Supporting teachers with disabilities.." - organization

Other Key Solutions

"Financial support to education must be increased. Tax deductions should be made enhanced for privately funded educational supports." - parent

Lack of Ownership and Active Engagement

Three-quarters of the organizations said that this issue was relevant to their work; while two-thirds of parents said that this issue was relevant to their concerns.

The top solutions endorsed on this topic were:

- Providing evidence-based strategies to support advocacy
- Developing programs to enable youth to develop self advocacy skills and to connect with the disability community
- Holding public consultations and policy dialogues with youth and evaluating such programs
- Raising awareness on rights-based approaches and the social model of disability

Example of Importance

"We work with young men and women who want to advocate for themselves yet lack the resources or strategies to do so." - organization

Comment on Solutions

"Participation in decision making promotes buy in and enhances self esteem." - parent

Other Key Solutions

"Creating connections between youth and role models / supports to encourage advocacy." - organization

"The lack of ownership isn't always due to lack of interest. I would love to be a better advocate for my children, to keep them involved in community activities and keep inclusion in the forefront of our lives. But I am sleep deprived, drowning in paperwork and burnt out already from this lifestyle. Meet us where we are. And we will gladly give you the information you are asking for." - parent

Leisure Activity Participation

The majority (83%) of organizations said that this issue was relevant to their work; similarly, the majority (88%) of parents said that this issue was relevant to their concerns.

The top solutions endorsed on this topic were:

- Training physical education and community leisure providers on strategies to better address specific needs
- Developing and implementing policies promoting participation in leisure for children with disabilities
- Providing early and cost-effective community-based interventions

Example of Importance

"Recreation is so important for all children, and particularly for children with disabilities. Yet many children spend phys-ed classes keeping score, are unable to play on inaccessible playgrounds and lack the equipment and support to participate in leisure activities.." - organization

Other Key Solutions

"Identifying children with disabilities within communities so that providers can reach out with information and services. Providing equipment e.g. sport wheelchairs for those children." - organization

"Every disability is so different, you can't label what inclusion looks like, as it varies so so much" - organization

Comment on Solutions

"'Inclusion' as a an art, science, and skill is takes training and reflection and insight. [It takes] very deliberate and intentional thoughts and actions that are seldom including in any sector or profession." - organization

"We are so behind the ball on simply having basic services available to families and children with disabilities, it seems like a frivolous ask to have 'leisure activities' be a focus." - parent

Lack of Public Participation

Almost all (92%) organizations said that this issue was relevant to their work; similarly, almost all (94%) of parents said that this issue was relevant to their concerns

The top solutions endorsed on this topic were:

- Ensuring that the voices, perspectives and experiences inform policy development and programming
- Facilitating participation in policymaking (e.g. consultations, hearings, public sessions and advocacy)
- Developing strategies that provide physical access to participate in public life
- Providing adequate levels of resources and services that support health and wellbeing
- Implementing positive approaches that encourage participation, reduce risk behaviours and increase thriving

Other Key Solutions

"Attitudinal changes are important but engaging people through empathy and experiential understanding can be a catalyst to change. Ensuring inclusion takes a creative, team-oriented approach to identify lagging skills and environmental issues, and to develop an intervention plan." - organization

"Including family voices and giving families the avenues to promote advocacy for children with disabilities can only produce positive change that is meaningful and worthwhile. It should be a mandate to include the opinion of those people affected by these policies and therefore make policymakers directly accountable for their work." - parent

Comments on Solutions

"My experience with families is that by the time their child reaches mid- elementary school, they are tired of fighting with systems to ensure the rights of their children. If you are only 20% of the population, you are starting your fight as a minority and families express that fighting for equal treatment is exhausting. Even as 20% of the population, many of the battles are fought by one parent and 9 times out of 10 I witness them finally resigning themselves to accepting less." - organization

"A child needs the opportunity to be integrated with peers, to learn important social skills and practices in order to become a functional part of a community. What that actually looks like for each child with a disability will be different but is still worth the effort and time to give them this opportunity." - parent

Using Rights-based Language and Approaches

83% of organizations and 93% of parents said "Using human rights language and principles to inform laws, policies, and practices" is important or very important.

92% of organizations and all the parents said "Developing concrete mechanisms for Canada to meet its obligations in regards to the CRC and CRPD" is important or very important.

Example of importance

"It would be helpful if the weight of legislation was there to help us in dealing with daily discrimination more effectively." - organization

Comment on Approach

"Policy may sound great in legislature but is open to interpretation [...] Measure qualitatively through patient satisfaction and interpretation." - parent

"[The] concrete part so important. Really needs some very clear concrete steps and ways to use Charter and legislation to implement. Can talk policy all you want." - parent

Application

"I love that as an employer I am now expected to provide AODA training to my staff and think it was absolutely the right decision to add volunteers to this expectation. It is now a matter of course; as important as health and safety, a job description and employee benefits." - organization

Implementation Barriers

"There is currently a lack of monitoring; NGOs are working together on a shadow report, but also need a dedicated department at the federal level to monitor and assess. Currently, CRPD has no 'teeth'." - organization

Actionable Areas Identified in the Research Literature

The Convention for Rights of Persons with Disabilities (CRPD) spells out the rights of children with disabilities that must be integrated horizontally into all other articles of the Convention (Stein, 2007).

Policies have been developed based on stakeholder consultation or compilations of population-based data, with a limited use of research-based information (Shikako-Thomas & Law, 2015). Framing disability issues in a social model, rather than a medical model that focuses on the individual impairment, places an emphasis on designing policies and environments that protect rights of people with disabilities (Jeon & Haider-Markel, 2001).

Below are 5 themes identified in a comprehensive review of the research literature related to right-based issues and actions that can be done to promote the rights of children with disabilities.

1 Youth and parent agency: awareness and engagement

Social inclusion in communities [implies] the rights to complete education, suitable labor work, mobility in the community and to make their own decisions.¹⁻⁸ Especially for youth, participatory rights and life skills will empower them to live more autonomously and independently³¹; including self-advocacy skills.³²

Self-advocacy enables youth to have a smoother transition into postsecondary education, into the workforce, and into becoming active leaders of change in their communities.²⁰ However, if the gains in competence acquired during the advocacy and consultation process are accompanied by lack of impact, which then results in a disillusionment that is itself negative for the individual and for society,²⁴ Thus, a conduit to translate action into meaningful change is necessary.

Actionable Items

A supportive parenting approach teaches the child self-agency and the importance of working might lead to more autonomy and employability.⁷

Empowering self-advocacy: there is "insufficient self-advocacy of a large number of persons with disabilities."⁴⁰

The CRC recommends that Canada pursue and develop its policy aimed at disseminating information and increasing public awareness of the Convention. It recommends that a nationwide education campaign be launched to sensitize the population at large (UN Committee on the Rights of the Child 1995, Section D-19)

Increase the availability of culturally relevant services to families of those living with disabilities of different ethnic backgrounds; positive models exist.³⁹

3 Promoting active citizenship by universal design

The Convention on the Rights of Children enshrines the right to community integration and the right to family life in Article 23, mandating states to support service provision that ensure opportunities of children to engage with their peers and to remain with their family.³⁸

To achieve this, universal design principles (i.e. equitable, flexible, simple and intuitive, perceptible information, tolerance for error) target changes in the environment rather than the individual are needed.⁹ This approach to service provision policy can maintain a level of solidarity and social inclusion, ultimately alleviating poverty over the long term. If universal policy is inclusive, specific policy for traditionally excluded groups would not be necessary.

Actionable Items

Planning and monitoring infrastructure design with an awareness of factors that facilitate universal design principles⁴⁻³⁶ and accountability mechanisms.³⁶⁻³⁷ Specific areas include public transportation,¹⁰ urban decision making.⁴²

The implementation of a social model of disability horizontally in the policy-making process would promote the realization of human rights for other vulnerable groups such as immigrants and direct the loci of responsibility of social inclusion and economic opportunities of the society as a whole.³⁰

South Africa leads as a role model for including disability social and political rights into its constitution.²⁴

2 Individual supports and reasonable accommodation

The Supreme Court has deemed support programs that people with disabilities need is an essential component of equality.¹⁰ Generally, reasonable accommodations lie in the medical model of disability rather than in the social model – meaning those approaches address barriers and needs that stem from the pathology rather than addressing environmental factors. However, the environment continues to have a role in reasonable accommodation.

Actionable Items

Mandating that reasonable accommodations in community spaces that go beyond non-discrimination practices to ensure more affirmative equality²⁵

Ensuring access in the legal system by providing sign-language interpreters, having physically accessible courts, and providing access to lawyers for disabled persons in rural communities.²¹

Working towards a comprehensive federal support that includes consultations with persons with disabilities, awareness-raising measures, accessibility standards, income support and tax measures, the Canada Social Transfer, support for victims of crime, and the Employment Equity Act²⁹ as well as welfare payment for caregivers.³ Further, the right of adequate income can be pursued through a comprehensive disability program, health-care reform, employment equity and accessible transportation system.³⁵

Creating an Accessibility Fund where money would come from fines collected due to violation of accessibility codes of buildings and would be used to ensure the full accessibility of public buildings.³³

Having permanent unemployment as a criteria to financial assistance could create important disincentive to participate in programs that aim at increasing life and work skills.⁶

4 Person- and family-centered approaches

A person-centred approach means that an individual's unique needs are identified and that the individual is involved in plans to address those needs. This approach encompasses a lifespan strategy³⁻¹⁵ to facilitate thriving in all spheres of life.²⁻³⁹

In particular, the family unit is a powerful determinant of future outcomes for children,⁴⁻⁴⁶ influencing health and wellbeing while reducing medical service use.^{14, 27} Thus, a family-centred approach in care emphasizes "the best environment for optimal growth and development for children in most circumstances."⁴³

Actionable Items

Encouraging services to move beyond being child-centred to family-centred, and beyond family involvement heavily reliant on moms¹⁷

Caregivers should be encouraged to actively participate in decision and policy-making process^{12, 23} and service evaluation.^{13, 43}

Effective transition planning is paramount to maximizing post-school outcomes.³⁴

Understanding who can and cannot be identified as a child with disabilities is crucial for families to access service provision.¹⁸

5 Service provider capacity building and coordination

A lack of information is a barrier to accessing continuous and routine care.^{13, 17, 23, 39, 41, 43} At the provider level, poorly qualified staff on disability issues and lack of knowledge about best practices in disability support are barriers to adequate service provision.¹⁶ Having various experts to work on a common purpose in a collaborative manner will relieve caregiver burden and facilitate access to information and care.^{11, 12}

Actionable Items

Creating databases to share community information¹¹, interagency hub¹³ and families' network²⁸; for example, a program called "Publicity Plan" facilitates access to up to date information about policies and programs for families and providers.³⁴

Evaluation of care should include an axis focusing on information sharing modalities and families perceptions of access to information.¹⁷

Integration of NGOs across disabilities to strengthen advocacy and impact of programs²⁸

Ensure the horizontal implementation of programs following inter-departmental policies addressing children with disabilities through cross-departmental coordination and accountability.³⁷

Provide Training opportunities in information-seeking skills⁴⁴, advocacy training³⁸, education on their rights, as well as about accessing the legal system to assert⁴⁵

Promote experience-sharing amongst multidisciplinary professionals^{5, 23}

Invest in sustained learning for providers to have up-to-date best practices, promote skills related to care provision such as flexibility and self-care and encourage information dissemination⁵

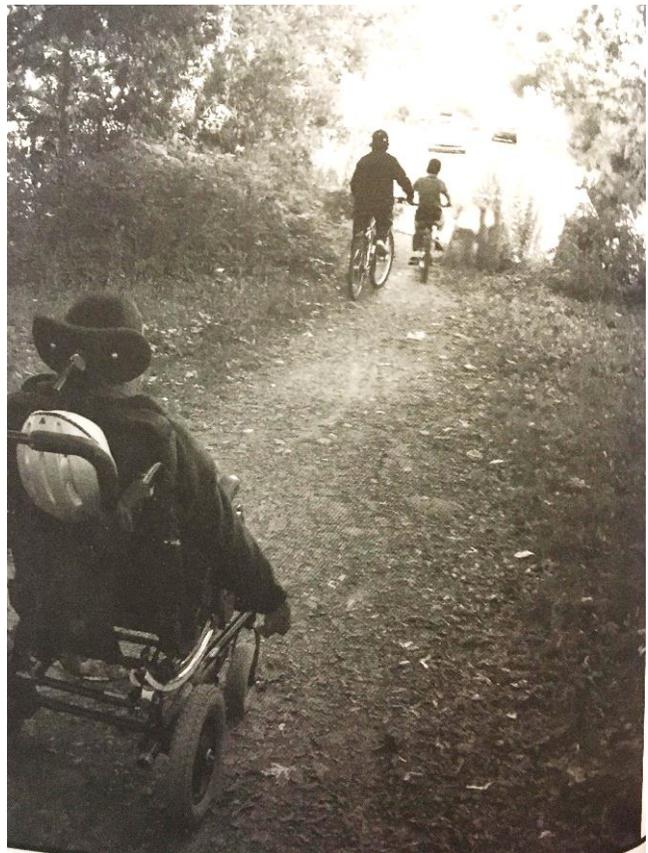
The Voice of Youth

We asked young people what was their understanding about their rights as individuals with disabilities, and what aspects were respected or not respected. We asked them to take pictures of images in their daily lives that could illustrate the presence or absence of these rights, and to talk to us about what they captured.

Five youth with disabilities between 16 and 22 years of age participated in this part of the study.

The youth told us that they experienced social exclusion in different situations, when compared to their non-disabled peers and siblings. Youth understood their rights were not being respected when there were social activities they could not participate in due to:

1. Inaccessible physical spaces: many spaces in the community, including those that claim to be accessible, cannot be accessed independently by a youth in a wheelchair or other limitations. Most pictures taken by youth show how their human right to "come and go" as they wish is constantly being violated.
2. Transportation: Poor accessible transportation options were related to the right to come and go. Even though some buses were equipped with technology to accommodate wheelchairs, these ran infrequently and youth felt that, overall, the drivers and passengers acted as though accommodating a person in a wheelchair was an inconvenience. Newer metro trains were described as lacking tie-down facilities which made youth feel extremely unsafe. Furthermore, scheduling adapted van services (an alternative to using 'regular buses or the metro') was experienced as a process that nearly always proved frustrating, causing participants to miss appointments or activities on a regular basis. One youth who had travelled by plane to visit family abroad found that the airline seemed to be ill-prepared to accommodate him and it was exhausting to endure additional levels of security and multiple transfers from one wheelchair to another during the process of getting boarded.
3. Social stigma and intolerance: Lack of awareness about disability and the presence of people with disabilities in many main stream activities contributed to a sense of stigmatization and intolerance of the public at large in many situations. Several noted they were frequently stared at. Robert said: "It's kind of weird. It makes me feel bad. Sometimes, I tell them to back off". This topic speaks to youths' right to represent themselves and develop agency by increasing awareness of disability in the society at large.
4. Opportunities to participate in the community and active living: Youth voiced their limited opportunities to engage in their communities and to do activities outside their home because of disabling societal structures. A common scenario was spending summers in the house playing videogames instead of interacting and participating in the community. Youth had ideas to address these situations: providing mobility equipment that would support their participation in outside activities, creating spaces and programs that were welcoming and having people listen to their opinions on the matters that impact them.



References

1. Al-Heresh, R. & Wendy, W. (2003). Community-based rehabilitation in Jordan: challenges to achieving occupational justice. *Disability & Rehabilitation*, 35(21), 1848-1852.
2. Badia, M., Orgaz, B. M., Verdugo, M. A., Ullán, A. M., & Martínez, M. M. (2011). Personal factors and perceived barriers to participation in leisure activities for young and adults with developmental disabilities. *Research in Developmental Disabilities*, 32(6), 2055-2063.
3. Baker, D.L. (2008). Issue definition in rights-based policy focused on the experiences of individuals with disabilities: An examination of Canadian parliamentary discourse. *Disability & Society*, 23(6), 571-583.
4. Baker, K. & Donnelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society*, 16(1), 71-85.
5. Bakare, M. O., et al. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics* 9: 12.
6. Beatty, H. (1999). Ontario Disability Support Program: Policy and Implementation. *Journal of Law and Social Policy*, 14, 1-68.
7. Berrey, E. & Nielsen, L.B. (2007). Rights of Inclusion: Integrating Identity at the Bottom of the Dispute Pyramid. *Law & Social Inquiry*, 32(1), 233-260.
8. Bérubé, M. (2009). Citizenship and disability. *Disability: The Social, Political, and Ethical Debate*, 205-213.
9. Bickenbach, J.E. (2014). Universally designed social policy: When disability disappears? *Disability & Rehabilitation*, 36(16), 1320-1327.
10. Chadha, E. (2005). Running on Empty: The Not So Special Status of Paratransit Services in Ontario. *Windsor Rev. Legal & Soc. Issues*, 20, 1-40.
11. Cigno, K., & Gore, J. (1999). A seamless service: meeting the needs of children with disabilities through a multi-agency approach. *Child and Family Social Work*, 4, 325-336.
12. Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation*, 24(10), 542-549.
13. Dowling, M. & Dolan, L. (2001). Families with Children with Disabilities – Inequalities and the Social Model. *Disability & Society*, 16(1), 21-35.
14. Eklund, K., Sonn, U., & Dahlin-Ivanoff, S. (2004). Long-term evaluation of a health education programme for elderly persons with visual impairment. A randomized study. *Disability & Rehabilitation*, 26(7), 401-409.
15. Engel, D. M. & Munger, F. W. (1996). "Rights, Remembrance, and the Reconciliation of Difference." *Law & Society Review*, 30(1): 7-53.
16. Fisher, K. R., et al. (2012). Barriers to the Supply of Non-Government Disability Services in China. *Journal of Social Policy*, 41(1), 161-182.
17. Fordham L., Gibson, F., & Bowes, J. (2012). Information and professional support: key factors in the provision of family-centred early childhood intervention services. *Child: care, health and development*, 38(5), 647-653.
18. Goodley, D., & Runswick-Cole, K. (2011). Problematizing policy: conceptions of 'child', 'disabled' and 'parents' in social policy in England. *International Journal of Inclusive Education*, 15(1), 71-85.
19. Grenwelge, C. & Zhang, D. (2013). The effects of the Texas Youth Leadership Forum Summer Training on the self-advocacy abilities of high school students with disabilities. *Journal of Disability Policy Studies*, 24(3), 158-169.
20. Groce, N. E., et al. (2014). Inheritance, poverty, and disability. *Disability & Society*, 29(10), 1554-1568.
21. Hill, A. J. (2012). Are There Differences in Leadership Styles at Local, State and National/federal Levels Among Advocates for People with Disabilities? (Doctoral dissertation, Our Lady of the Lake University).
22. Hunt, P. and J. Mesquita (2006). Mental Disabilities and the Human Right to the Highest Attainable Standard of Health. *Human Rights Quarterly*, 28(2), 332-356.
23. Heap, M., et al. (2009). 'We've moved away from disability as a health issue, it's a human rights issue: reflecting on 10 years of the right to equality in South Africa. *Disability & Society*, 24(7), 857-868.
24. Heyer, K. (2002). The ADA on the road: Disability rights in Germany. *Law & Social Inquiry*, 27, 723-762.
25. Heyer, K. (2007). A disability lens on sociological research: Reading rights of inclusion from a disability studies perspective. *Law & Social Inquiry*, 32(1), 261-293.
26. Lee, L., Arthur, A., & Avis, M. (2007). Evaluating a community-based walking intervention for hypertensive older people in Taiwan: A randomized controlled trial. *Preventive Medicine*, 44(2), 160-166.
27. Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of pediatric health care*, 20(4), 245-252.
28. MacLachlan, M.M. & Mannan, H. (2014). The world report on disability and its implications for rehabilitation psychology. *Rehabilitation Psychology*, 59(2), 117-124.
29. Malhotra, R. H. & Robin F. (2011). United Nations Convention of the Rights of Persons with Disabilities and its Implications for the Equality Rights of Canadians with Disabilities: The Case of Education. *Windsor Y.B. Access Just.*, 29, 73-106.
30. Mosoff, J. (1998). Excessive Demand on the Canadian Conscience: Disability, Family, and Immigration. *Man. L.J.*, 26, 149-180.
31. Munro, E. et al. (2011). The contribution of the United Nations Convention on the Rights of the Child to understanding and promoting the interests of young people making the transition from care to adulthood. *Children & Youth Services Review*, 33(12), 2417-2423.
32. Patterson, L. (2012). Points of access: Rehabilitation centers, summer camps, and student life in the making of disability activism, 1960-1973. *Journal of Social History*, 46(2), 473-499.
33. Philipps, S.D. (2009). Civil society and disability rights in Post-Soviet Ukraine: NGOs and prospects for change. *Indiana Journal of Global Legal Studies*, 16(1), 275-291.
34. Poon-McBrayer, K.F. (2012). Bridging policy-practice gap: Protecting rights of youth with learning disabilities in Hong Kong. *Children and Youth Services Review*, 34(9), 1909-1914.
35. Porter, B. (2005). Twenty years of equality rights: Reclaiming expectations. *Windsor Y.B. Access Just.*, 23, 145-192.
36. Prince, M.J. (2002). The governance of children with disabilities and their families: Charting public-sector regime in Canada. *Canadian Public Administration*, 45, 389-409.
37. Prince, M.J. (2004). Canadian disability policy: Still a hit-and-miss affair. *Canadian Journal of Sociology*, 29(1), 59-82.
38. Rosenthal, E. et al. (1999). Implementing the right to community integration for children with disabilities in Russia: A human rights framework for international action. *Health and Human Rights*, 4(1), 82-113.
39. Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education*, 30(3), 144-149.
40. Sabatello, M. (2005). Reviewed work: The human rights of persons with intellectual disabilities: Different by equal by Stanley S. Herr. *Human Rights quarterly*, 27(2), 737-749.
41. Shikako-Thomas, K. & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: From policy to play. *Disability & Society*, 30, 1-20.
42. Stephens, C.C. et al. (2012). Urban inequities; Urban rights: A conceptual analysis and review of impacts on children and policies to address them. *Journal of Urban health*, 89(3), 464-485.
43. Thyen, U., Sperner, J., Morfeld, M., Meyer, C., & Ravens-Sieberer, U. (2003). Unmet health care needs and impact on families with children with disabilities in Germany. *Ambulatory Pediatrics*, 3(2), 74-81.
44. Tsai, E. H. L., & Fung, L. (2009). Parents' experiences and decisions on inclusive sport participation of their children with intellectual disabilities. *Adapted Physical Activity Quarterly*, 26(2), 151-171.
45. Vilchinsky, N. & Findler, L. (2004). Attitudes toward Israel's equal rights for people with disabilities law: A multiperspective approach. *Rehabilitation Psychology*, 49(4), 309-316.
46. Weisz, V. & Tomkins, A. J. (1996). The right to a family environment for children with disabilities. *American Psychologist*, 51, 1239-1245.

about us

The PARTICipation and Knowledge Translation - PAR KT Lab is based at McGill University and the Center for Interdisciplinary Research in Rehabilitation of the Greater Montreal (CRIR) and is led by the Canada Research Chair in Childhood Disability: Participation and Knowledge Translation that does research aimed at improving the health of Canadian children with disabilities by engaging different stakeholders and connecting academic research and policy.

This brief was created by Jonathan Lai (PhD), CIHR Health System Impact Fellow, McGill University.

contact information

Keiko Shikako-Thomas, PhD, OT,
Canada Research Chair in
Childhood Disability: Participation
and Knowledge Translation
keiko.thomas@mcgill.ca

This project was funded by



with infrastructure support from

