Rights-based approaches in childhood disabilities

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Context

• 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 Convention on the Rights of Persons with Disabilities (CRPD): the social model of disability and the notion of inclusion and expands on the CRC for this population.

• Implementation in Canada has been limited

• A new disability legislation is being developed in Canada

Shikako-Thomas & Shevell (2018). *Seminars in Pediatric Neurology*
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Research Literature Review

These topics were identified in the research literature:

- Access
- Types
- Goals
- Coordination
- Quality
- Stakeholder Involvement
- Resource Distribution
- Legislative Support
- Education
- Health
- Social

Actionable Topics Identified:

- Assistive technology
- Client-centered approach
- Coordinated approach: multi-agency care
- Financial assistance
- Integration and mainstreaming
- Family-centered model
- Full citizenship
- Measuring success
- Employment
- Reasonable accommodation
- Youth engagement and agency
- Provide information
- Awareness through training
- Universal Design
- Quality Improvement for services

Adopt strategies that promotes human rights for children across the entire lifespan.

Solutions were grouped into 5 categories:

- Youth and parent agency: awareness and engagement
- Individual supports and reasonable accommodation
- Person- and family-centered approaches
- Promoting active citizenship by universal design
- Service provider capacity building and coordination

112 academic articles were analyzed

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Connecting Rights and Needs

**Themes**

**INCLUSION**
- Social Inclusion
- Inclusive Education

**PARTICIPATION**
- Participation in Public Life
- Participation in Leisure

**FAMILY SUPPORT**
- Family-centered approaches
- Supports systems and community integration

**Frameworks**

The Convention on the Rights of Persons with Disabilities (CRPD, 2001)


- Social Model of Disability
- WHO’s International Classification of Functioning (ICF)

**Equity Considerations**

Intersectionality

Children x Disability
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Stakeholder consultations: Raising awareness and validating actionable items

Researchers consultation (law, human rights, rehab, disabilities, social work):
scarcely use of “rights” language in health research and practice
Legal aspect not health, education, participation → occupations!

Grassroots organizations survey (N=107) disability organizations across Canada

Parents survey (N=33)

Youth focus group and photo elicitation

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**Stakeholder consultations:** the priority actionable solutions that promote the rights of children with disabilities

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

<table>
<thead>
<tr>
<th>Percentage of Organizations</th>
<th>Percentage of Parents</th>
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</thead>
<tbody>
<tr>
<td>Measuring inclusion into communities as an indicator of success for interventions</td>
<td>93</td>
</tr>
<tr>
<td>Using international human rights guidelines to guide standards of services</td>
<td>93</td>
</tr>
<tr>
<td>Using international human rights guidelines to evaluate Canadian policies</td>
<td>93</td>
</tr>
</tbody>
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“You have to measure the full citizenship - what are the markers of full citizenship, and include that in policy.”
- parent

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

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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).

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).

**Solutions:**
- 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

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

“Participation in decision making promotes buy in and enhances self esteem.” - Parent
Policy Dialogues

- Creating space for discussion, awareness, knowledge translation

→ Policymakers at provincial and federal level
→ UN Conference of the States Parties for the CRPD

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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.
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MERCI!