Communication, coalition and cooperation:
Conference on Innovating and Developing Disability Policy Research
Beijing, China
January 14, 2017
Overview & background on CDPA

• The Canadian Disability Policy Alliance began informally in 2006.

• Authors on the book, *Disability & Social Policy in Canada* (McColl & Jongbloed, 2006, Captus Press) sought a way to continue working together toward better social policy for people with disabilities in Canada.

• In 2009, the Alliance was funded by the Social Sciences and Humanities Research Council of Canada.

• In 2014, the CDPA joined another national initiative, the Canadian Disability Participation Project, to secure funding to 2021.
What was our over-arching purpose?

The vision for CDPA is a vision of Canada “where people with disabilities enjoy full participation and citizenship, supported by a coherent framework of legislation, regulation and programs.”
What was our over-arching purpose?

To achieve that vision, we identified 3 goals:

1. **Knowledge Creation** - To synthesize evidence and, where necessary, generate new knowledge regarding disability policy in Canada and its impact on the lives of people with disabilities.

2. **Knowledge Dissemination** - To share knowledge with policy makers and other stakeholders to enhance accessibility and inclusion for people with disabilities.

3. **Training and Development** - To develop capacity in the areas of policy analysis, disability studies and collaborative research among students, staff, partners associated with the CDPA.

A vision of Canada where people with disabilities enjoy full participation and citizenship, supported by a coherent framework of legislation, regulation and programs.
How did we decide who to invite to join us in our mission?

- We did not seek representativeness or a formal structure when identifying members for the Alliance.

- We invited people that:
  - we knew and trusted,
  - we had worked with in the past,
  - shared our goals and aspirations.

- We sought partners who wanted to work hard and get the job done!
How did we decide who to invite to join us in our mission?

- Academic partners: Queens University, UBC, University of Regina

- Community partners: Easter Seals, March of Dimes Canada, Spinal Cord Injury Canada, Lésions Médullaires Canada, Canadian Association for Community Living

- Policy partners: Government of Canada, Ontario, Social Sciences and Humanities Research Council

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How did we define disability?

- Focus on disabilities arising from physical, sensory and cognitive impairments.
- Our guiding principle is “inclusivity”.
- We seek to use language that invites others into the dialogue, and that welcomes a variety of perspectives.
- We refer to federal guidelines for non-discriminatory language.
- We are guided by our community partners and the preferences of their members.
- We seek neutrality and clarity of communication in language.

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Core assumption #1:
People with a variety of expertise and skills are needed to make a difference in achieving effective disability policy:
• disabled consumers, their advocates and support systems;
• disability researchers and trainees;
• policy experts and public servants.
How did we work together?

- **Academic partners:** Identify research questions; Recommend methodology; Undertake literature review; Seek funding as necessary; Conduct policy analysis & prepare policy briefs; Publish and present research findings
- **Community partners:** Identify important problems faced by their members; Shape results to impact needs and lives of consumers; Reaching out to policy-makers; mobilize their members and distribution networks
- **Policy partners:** Assist in understanding the policy environment; Identify appropriate contact persons within government; Assist in framing messages; Assist in understanding the timelines

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How did we work together?

The Learning Collaborative methodology

1. **Plan** – To assemble the best policy-relevant evidence available, by conducting policy analysis, comparing jurisdictions, identifying best practices, reviewing international literature. *(ACADEMIC PARTNERS)*

2. **Do** – Engage policy makers, and provide them evidence-based policy briefing; make recommendations for best practices. *(CONSUMER PARTNERS)*

3. **Study** – Study the effectiveness of this initiative, and gather new information from policy-makers about how this could be done more effectively. *(ACADEMIC & POLICY PARTNERS)*

4. **Act** – Broaden the reach of the initiative to include other jurisdictions, other disability groups, other policy sectors. Refine knowledge mobilization instruments and approaches. *(ALL PARTNERS)*

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What specific methodologies did we use?

**Core assumption #2:**

We already know most of what is needed to support effective disability policy in Canada. In most instances, the research is already available to provide evidence for good, sound disability policy.

What is needed is context-specific, policy-relevant synthesis of the research.
What specific methodologies did we use?

We developed a number of research tools that assisted us in this work, and that are freely available on our website:

http://www.disabilitypolicyalliance.ca/

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What specific methodologies did we use?

Cross-jurisdictional policy scans

• Clara, N., & Misiorowski, J. (2010). Disability and health services policy analysis.

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What specific methodologies did we use?

The disability policy lens
This is a quick, easy guide to assessing the implications of policy decisions for people with disabilities.

It offers a series of questions derived from “Tips for policy analysis” (in McColl & Jongbloed, 2006. Disability and social policy in Canada (2nd ed.).

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What specific methodologies did we use?

Timeline of disability policy in Canada

Since 1975, there have been many policy events that have aimed towards a more inclusive Canada. The interactive timeline displays federal disability policy events over the last 4 decades. Click and explore!

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What specific methodologies did we use?

Outcome measures and instruments

In order to conduct the work of the CDPA, a number of measures have been developed and validated.

- **The Accessible Elections Checklist** -- for a study of electoral accessibility in Ontario;
- **The Community Integration Measure** -- for studies of overall participation in community living for people with disabilities.
- **The Main Street Accessibility Checklist** -- to study the impact of the Accessibility for Ontarians with Disabilities Act on a small community.
- **The Primary Care Accessibility Checklist** -- for studies aimed at improving access to primary care.
- **Hotel & Meeting Room Accessibility** -- to guide our choices of meeting venues, processes & accommodations.
- **The Time Use Index of Disability Integration** – using national survey data, an index of the extent of integration of disabled people in a population.

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How did we decide what research questions to focus on?

**Core assumption #3:**
The policy environment is perfectly designed to produce the problems that disabled people experience!

In other words, most of the problems experienced by people with disabilities can be tracked back to a problem in the policy environment.

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How did we decide what research questions to focus on?

The CDPA originally began with a focus on five areas of policy, based on the expertise of its researchers and the strategic priorities of its community partner organizations:

• Employment
• Health
• Culture & recreation
• Education, and
• Federal policy

We have subsequently added two areas of focus:

• Mobility
• Sport & physical activity.

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How is the partnership governed?

1. Governance -- The Alliance is governed by an assembly of the founding partners who oversee activities, ensure compliance with funder requirements, and monitor progress.

2. Meetings -- We are committed to meeting face-to-face semi-annually. Our meetings are fully accessible. There is an emphasis on hospitality and collegiality when we meet. Expenses are fully covered for meetings.

3. Decision Making -- Wherever possible decisions are made by consensus. We seek to ensure everyone feels heard, and can live with the outcome of a decision.

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5. Communication -- We urge open, honest and direct communication. We seek to maintain a high degree of trust among the partners. All media communications are coordinated through the Secretariat.

6. Position Statements -- The Secretariat has been empowered to make public statements on behalf of the CDPA. If it is inevitable to publicly contradict the stated position of a partner, we will contact them prior to release to let them know the rationale.

7. Conflict Resolution -- If decision-making is being held up, or if conflict is becoming destructive, a process will be undertaken to resolve conflict.
How is the partnership governed?

8. Conflict Of Interest -- The opportunity for conflict of interest arises when a partner uses membership in the Alliance to derive personal financial benefit, OR Alliance duties conflict with partners’ duties to their affiliated organization. We respectfully request that partners advise the Secretariat if they are in a conflict of interest.

9. Roles and Relationships -- Roles and relationships should be negotiated at the outset of a project. We offer guidelines for research roles, authorship, intellectual property and ownership.
How is the partnership managed?

1. Central administration -- The day-to-day operation of the Alliance is the responsibility of the Secretariat – made up of the Academic Lead, the Community Lead and the Alliance Manager.

2. The only paid position in the Alliance is the Manager. All others donate their time either as part of their research role within their university, or as an in-kind contribution by their organization.

3. Resources to fund specific projects came primarily from external grants, with the exception of small allocations to the Team Leads for start-up expenses.

4. Scholarships were provided annually on a competitive basis, to 2-3 graduate students studying disability policy.
On behalf of the Canadian Disability Policy Alliance, thank you for this opportunity.

For further information on the Alliance or on the work we have done over the past 7 years, please visit us at: www.disabilitypolicyalliance.ca

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