



# Borders, Bridges, Barriers and Brains: Stakeholder Issue Definition in Rights Based Policy Related to Autism

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## Project Abstract

In issue definition related to rights based policy, Canada has been stereotypically understood as taking a more positive, human rights centered approach whereas the United States has been expected to take a more negative, civil rights based tact. While this difference in approach is expected to be a key to a broad base of differences between the two nations and societies, the difference is arguably unusually relevant in the disability policy arena. After all, recent changes in the understanding of disability is transforming disability from an issue of personal culpability overseen by medical professionals and tempered by charitable efforts to an issue of shared social and personal construction for which society at large is responsible. As the incidence of disability continues to rise, broad changes in social, political, and economic infrastructures are the expected result of recent innovations in disability related policy. These changes will affect society well beyond the lives of individuals with disabilities. Over the past decade, Canada, the United States and several other countries have experienced a surge in the reported incidence of autism. The public management of needs related to the autism baby boom is an unfolding process. This project examines how the current definition of rights in the realm of autism policy fits into the ongoing history of the definition of human and civil rights in North America.

## Guiding Research Question

Does the stereotypical difference between the Canadian and American approach to the construction of rights manifest in autism issue stakeholders' experiences? If so, how?

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## Project Context

- ❖ **Disability amalgam:** Disability has become understood as being jointly created by individuals' characteristics and public infrastructures designed—intentionally or not—to exclude those whose bodies, minds or behaviors deviate from the norm.
- ❖ **Establishing rights:** Canada and US have distinct histories of rights' creation, rooted in differing democratic systems.
- ❖ **Policy challenge:** **Change in understanding of disability and difference in rights basis is especially relevant for non-physical disability since solutions lie beyond ramps.**

## Autism Policy History

- ❖ **Multiple arenas:** Challenges related to autism that have been defined as public issues are usually addressed using civic education, services or purely rights based policy solutions.
- ❖ **Recent policy presence:** More targeted policies on both sides of the border. Examples include tax credits, license plates, Medicaid waivers, Homeland Security Act
- ❖ **Canadian Supreme Court Case:** Auton v. British Columbia, decided in November 2004, sought to establish access to applied behavior analysis therapy as a medical right

## Methodology

- ❖ Surveys and semi-structured interviews
- ❖ Respondents include parents and primary caregivers and professional issue stakeholders
- ❖ Surveys correlated with the Participation and Activity Limitation Survey (PALS) from Statistics Canada
- ❖ Current analysis is of 618 surveys of parents and primary caregivers' responses and 31 interviews

## Survey Participants

- Socio-economic composition mirrors larger population in British Columbia and Missouri (areas chosen for preliminary study)
- Majority of respondents had boys (83% Can. & 84% US)
- Most parents in both countries began to suspect a developmental difference in their child between the ages of 6 months and 2 years
- Most families experienced a gap of 12-18 months between initial suspicion and official diagnosis
- Most families' recorded no autism in family before current generation of children (74% Can & 70% US)

## Selected Findings

- Canadian parents/primary caregivers reported more frequently that their child's rights had been violated as a result of his or her autism (56% Canada & 38% United States)
- A similar percentage in both countries reported their family's community activities were restricted as a result of their child's autism (73% Can & 78% USA)
- In the United States, parents were almost twice as likely to report rights violations if they also reported their community activities were restricted (no correlation observed in Canadians' experiences)
- A similar percentage in both countries reported unmet service needs (72% Canada & 70% United States)
- More Canadian children with autism reported to be fully included in general education classrooms (69% Canada & 26% United States)