## Enforcing the Rights of People with Disabilities in Ontario's Developmental Services System

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## **SUMMARY**

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This paper begins by providing a history of Ontario's approach to providing services and supports to people with intellectual disabilities, in particular the impact of 2008's *Services and Supports to Promote the Social Inclusion of Persons with Disabilities Act*, which is being proclaimed in three stages ending July 1, 2011.

The focus of this legislation is on the delivery of community-based developmental services and supports and the provision of direct funding to enable people with disabilities and/or their families to purchase and direct services and supports of their choosing.

The author concludes that the Act fails to truly transform the developmental services sector but rather maintains a system of services that reflects elements of both the medical and social models of disability. Joffe says that the medical model continues to dominate the legal definition of intellectual disability, and the power to determine who is eligible to receive services or funding remains in the hands of medical professionals.

She is also concerned about the manner in which the Act treats the right of people to make their own life decisions and to have information about themselves remain confidential. As she writes: "Denying people the right to make their own life choices usurps independent decision-making. People with disabilities are denied the opportunity to gain decision-making skills, make mistakes and learn from those mistakes, learn self-advocacy skills and assert their rights."

However, the most serious concern about the Act, according to Joffe, is that it fails to include any rights for people with disabilities when they receive developmental services and supports.

The paper looks at the continuing barriers that impede the realization of the entitlements set out in the legislation. In particular, the author points out that people with disabilities continue to face discriminatory attitudes and to have difficulty establishing a culture in which service providers and community members respect the right of people with disabilities to self-determination.

She also identifies fear or retaliation or reprisal as a significant barrier for people who want to raise concerns about services they are receiving.

Joffe identifies a number of times in the paper the particular challenges faced by people who have communications disabilities. "People must also be trained to experiment with and use alternate forms of communication. Far too often, people who are non-verbal are assumed to lack capacity simply because they do not speak. However, research has demonstrated that using creative ways to communicate with a person with an intellectual disability can enable the person to make independent and autonomous decisions."

Further, when discussing the need for services and supports to be individually tailored to meet the specific needs of each person with a disability, she writes: "Some people with disabilities do not speak. They may use Bliss Boards or electronic equipment to communicate. Service providers and others who interact with the person must know how to use these kinds of alternate communication devices in order to be able to provide appropriate services and supports. For some people with intellectual disabilities who do not speak, sometimes what is required of a support person is careful listening to sounds and spending time learning the cues and communication techniques that the individual employs."

Joffe sets out four reasons why including rights in the Act is important:

- 1. Symbolically, it demonstrates that the humanity and dignity of persons with intellectual disabilities is recognized in substantive rights
- 2. Practically, this is the first step towards creating a culture of rights within the developmental services sector
- 3. The first step towards enforcing rights is to enshrine them in legislation
- 4. Including rights in legislation helps to ensure that people with disabilities and service providers have similar expectations and standards.

She also identifies a number of minimum developmental service rights:

- 1. Right to live free from discrimination, harassment, abuse and neglect
- 2. Right to be provided services and supports in a manner that recognizes the person's individuality and responds to the person's needs and preferences
- 3. Freedom of choice regarding activities of daily living
- 4. Right to be informed in writing or other accessible method about programs, services, laws, policies and complain procedures
- 5. Freedom of choice about which services and supports to access
- 6. Right to enjoy personal privacy
- 7. Right to be free from confinement or restraint

- 8. Right to have personal decisions respected
- 9. Right to receive rights information in plain language and accessible formats
- 10. Right to make complaints
- 11. Right to enforce rights
- 12. Right to advocacy support service or legal services

Joffe considers the use of a human-rights based approach to enforcement mechanisms in the developmental services sector. After a lengthy review of why such an approach might be appropriate, the legal sources of a human-rights approach and the principles of Canadian human rights law, especially with respect to enforcing service rights, she concludes that adopting a human rights based approach has transformative potential. It could help to address the historical discrimination and segregation of this community and could change the role assigned to people with disabilities in the service delivery system, ultimately creating services that are more responsive to the needs of people with disabilities and accountable to them.

The paper includes a lengthy review of selected enforcement mechanisms in other jurisdictions.

The conclusion of the paper sets out key components in a strategy to enforce rights in Ontario's developmental services sector:

- Rights education for people with intellectual disabilities provided in plain language using multiple formats to ensure accessibility
- Detailed complaint mechanisms that are accessible to and useable by people with intellectual disabilities
- Appeals to an independent administrative body, with an accessible process including necessary accommodations
- Establishment of peer advocacy committees

Joffe makes the important point that each of these components must be implemented as they work together and are integrated with one another. It is her opinion that implementing these four components is achievable, based on the experiences from jurisdictions outside Ontario.