



Submission Re: Bill 175

Concerns with Patients' Rights

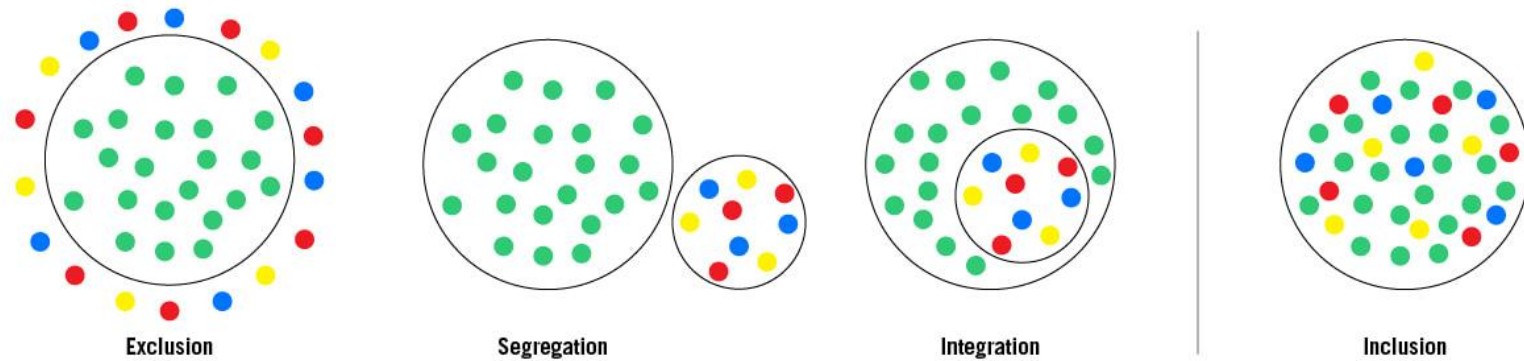
June, 2020

Introduction



- **Citizens With Disabilities – Ontario (CWDO)** was incorporated as a provincial not-for-profit organization on May 10, 2005.
- **CWDO is non-partisan**, with a **cross-disability focus**.
- **CWDO is the Ontario representative for the Council of Canadians with Disabilities (CCD)**. We participate in many CCD initiatives and support CCD's pan-Canadian efforts.

Vision Statement



Citizens With Disabilities - Ontario (CWDO) is committed to the rights of all persons to participate fully in the civil, cultural, economic, political and social life of their communities.

Image Credit: <https://www.inclusionontario.ca/what-is-inclusion.html>

Mission Statement

CWDO actively promotes the rights, freedoms and responsibilities of persons with disabilities through community development, social action, and member support and referral.

Our primary activity is public education and awareness about the social and physical barriers that prevent the full inclusion of persons with disabilities in Ontario.

Photo credit: www.coe.int



The Issue

- No consultation of Bill of Rights
- “Care” vs. “**services** to promote independent living”
- Language perpetuates stereotypes of persons with disabilities as objects of pity and charity
- Language entrenches “ableism” which undermines the value of people living with disabilities
- As current events illuminate, the existing Bill of Rights needs to be strengthened, not demoted to regulation
- Need to ensure broad consultation

Concerns

- “Care” vs. services to promote independent living
- Concern that “care” is paternalistic rather than rights based
 - No acknowledgement of self-directed service, autonomy
 - Relegates people with disabilities and seniors as “things” to be looked after or “cared for”
- I am not a patient unless I'm in a hospital or my doctor's office
- I AM A PERSON FIRST, WITH RIGHTS!

Validation of Concerns

Lack of Protection

- Fear of nursing homes - for example:
 - At 75, Arleen Reinsborough's fear of nursing homes has her more determined than ever to seek assisted suicide
 - <https://www.thestar.com/news/canada/2019/01/20/hamilton-senior-in-unbearable-pain-wants-assisted-dying-to-save-her-from-nursing-home.html>
- Nursing Home debacle exposed during COVID-19 Outbreaks
 - The Canadian Armed Forces' May 26, 2020 scathing report exposed the terrible conditions at five Ontario long-term care homes known by all - including government - for years
 - Abuses, cockroaches, Inappropriate care and more
 - <https://www.macleans.ca/wp-content/uploads/2020/05/JTFC-Observations-in-LTCF-in-ON.pdf>
- Murders - for example:
 - Serial killer nurse Elizabeth Wettlaufer slipped through cracks, even though concerns and complaints were raised
- Insufficient service levels for seniors and people with disabilities living in the community – Well documented

My Story

- 1966 – I was forced to leave home permanently at the tender age of 7 in order to access services not available in the community
- 1974 – I was told I would go to a nursing home at age 18 so had better get used to not having a say in how I would live
- 1976 – I was accepted into a pilot offering attendant services in the community
- As an adult, I was able to direct my own services, live my own life, pay my own rent and complete my education.
- 1981 on – Immediately after graduating became gainfully employed full time and continued working until I retired a years ago.
- Today - I constantly live in fear that community services will be cut back, and people like me will be forced back to institutions or that all the institutional rules will come to bear in our personal homes.
- Few policy makers understand the importance of community-based services, and of not treating us like we are sick in order to receive the services we need to live independently.

Protections Requested

1. Keep the word “services” in the Act
2. Entrench and codify “Rights for Patients, Consumers and Clients” in the Act
3. Hold broad consultation on the Act, including the “right” of people to receive and direct their attendant services
4. Recognize self-directed care models as well as medical models of service delivery
5. Keep institutions out of our homes while allowing services to flow in and out as needed

Outcomes: Language

If “persons” are recognized in addition to patients:

- Affirms the medical model is not the only model of service
- Validates that people with disabilities are not “sick” even though we need assistance with activities of daily living
- Addresses ableism and negative stereotypes attributed to people with disabilities
- Acknowledges that services are provided in multiple home and community settings
- Protects the self-directed model of service which supports people with disabilities to live in the community, with attendant services

Outcomes: Bill of Rights

If Bill of Rights Are Entrenched in the Act

- Higher authority
- Benefit of community consultation
- Higher accountability for service providers
- Better protection for patients and others who receive service in the community
- Assurance to families, patients and others who receive service in the community that there is recourse to address incidents

If Bill of Rights Are Delegated to Regulation

- Lowers authority
- Community consultation not required or could be very limited
- Less attention to rights by service providers
- Less protection for patients and others who receive service in the community
- No assurance to families, patients and others who receive service in the community that there is recourse if things go awry

Presenter

Tracy Odell

President

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Contact Information

Contact CWDO

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Social Media

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- Instagram: https://www.instagram.com/citizenswithdisabilities_on