

**John Dossetor
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Duty to Accommodate: The Ethical Imperative for a Human- Rights-Based Approach to Medical Care During the COVID-19 Pandemic, and Beyond

Health Ethics Seminar

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“We’re all in this together!” ... Unless you’re disabled

- ▶ The COVID-19 pandemic has laid bare the systemic ableism that relegates people with disabilities to the margins of both society and healthcare.



“We’re all in this together!” ... Unless you’re disabled

- ▶ Equally disturbing, and equally ignored by the vast majority of mainstream media, has been the development of critical care triage protocols which list the pre-existence of a disabling condition as an exclusion criterion for critical care, in the event that rationing of critical care resources becomes necessary due to a massive influx of critically ill patients with COVID-19.

“We’re all in this together!” ... Unless you’re disabled

- ▶ All of these things point to the fact that Canada suffers from a pre-existing condition that is making COVID-19 much more lethal for entire segments of its population. The name of this condition is ableism.

The Plan...

- ▶ Provide an overview of the concept of ableism.
- ▶ Look at the ways in which ableism functions to keep people with disabilities on the margins of Canadian society.

The Plan...

- ▶ Consider some of the ways in which common healthcare policy and protocol responses to COVID-19 can be seen to have ableist underpinnings, and often thus result in the exclusion and abandonment of people with disabilities.
- ▶ Consider the ethical imperative for a human-rights-based approach to healthcare policies and protocols related to COVID-19.

What is Ableism?

Ableism: Discrimination and social prejudice against people with disabilities based on the belief that typical abilities are superior.

What is Ableism?

- ▶ At its heart, ableism is rooted in the assumption that disabled people require ‘fixing’ and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as ‘less than,’ and perpetuates harmful stereotypes, misconceptions, and generalizations about people with disabilities.

“One of the Most Societally Entrenched and Accepted isms”

- ▶ Buildings are built to exclude people who do not walk or see.
- ▶ Students with disabilities are taught that it's better to look, move, and behave as much like their nondisabled peers as possible
- ▶ Terms associated with disability are used as insults in common parlance.

Ableism in Healthcare

- ▶ As individuals, healthcare professionals are not immune to the influence of dominant societal understandings of, and attitudes towards, individuals and groups of people deemed to be Others.

Ableism in Healthcare

- ▶ Galli and colleagues observe that “Despite their intentions, personal goals and normative expectations, even health professionals are unconscious bearers of implicit social biases that affect the quality of professional interventions.”

Problematic Medical Notions of “Quality of Life”

- ▶ Research indicates that people with disabilities frequently encounter discrimination in healthcare settings, even in ordinary times.

Problematic Medical Notions of “Quality of Life”

- ▶ As a group, health care professionals tend to substantially underestimate the quality of life of people with disabilities.
- ▶ Erroneous judgments about the quality of life experienced by people with disabilities can result in treatment options for people with disabilities being either limited, or altogether eliminated.

The “Ableist Conflation”

“Wherever operative, the ableist conflation flattens communication about disability to communication about pain, suffering, hardship, disadvantage, morbidity, and mortality.”

-- Joel Reynolds

“Common Sense” Ableism

- ▶ James Cherney argues that “ableism is that most insidious form of rhetoric that has become reified and so widely accepted as common sense that it denies its own rhetoricity; it `goes without saying.`”
- ▶ Within this milieu of “common sense” ableism, people with disabilities are routinely made vulnerable in medical settings.

The Tragic Death of Ariis Knight: An Instance of Lethal Ableism in the Wake of COVID-19



Evidence of Ableism in Critical Care Triage Protocols

- ▶ As these Critical Care Triage Protocols started to be rolled out last spring, it quickly became evident that the vast majority of them listed pre-existing disability as an exclusion criterion for critical care.

Evidence of Ableism in Critical Care Triage Protocols

- ▶ The clinicians and ethicists who crafted these protocols no doubt considered the decision to list pre-existing disability as an exclusion criterion to be well-supported by statistical evidence.
- ▶ Nevertheless, the resulting outcry and denunciation of these protocols from disability-rights advocates was both swift and unanimous.

ARCH Disability Law Centre's Recommendations

- 1. Persons with disabilities cannot be deprioritized for critical care on the basis of their disability.**
- 2. The Triage Protocol must clearly state that clinical judgment must not be informed by bias, stereotypes, or ableism.**
- 3. Persons with disabilities cannot be deprioritized for critical care based on the supports they receive for daily living.**
- 4. The Triage Protocol must clearly ensure that persons with disabilities receive necessary disability-related accommodations.**

ARCH Response to Triage Protocol #2 (July 2020)

1. **Non-discrimination** must be a guiding principle in its own right to ensure appropriate weight is given to human rights in triage decisions.
2. The Triage Protocol must **not rely on medical utility** as its primary guiding principle, as it leads to adverse consequences for persons with disabilities, and fails to consider systemic health discrepancies.

ARCH Response to Triage Protocol #2 (July 2020)

3. The framework must shift from a focus on the **intention not to discriminate to whether adverse impact (discrimination) flows** from the approaches embodied in Triage Protocol 2.
4. Ontario Health must communicate to every hospital and medical association/organization that the **Triage Protocol dated March 28, 2020 is not to be relied upon** or implemented.

ARCH Response to Triage Protocol #2 (July 2020)

5. **Clear language and plain language versions** of all drafts and the final version of the Triage Protocol are to be produced and distributed widely so that all relevant stakeholders are able to understand the information and provide feedback.
6. **Wider consultations** are to be undertaken by the Bioethics Tables to ensure that the perspectives of persons with lived experience from marginalized and disproportionately impacted communities are heard and inform the drafting of the Triage Protocol.

ARCH Response to Triage Protocol #2 (July 2020)

7. The Triage Protocol **must not rely on the Clinical Frailty Scale** in any capacity.
8. The Triage Protocol must **eliminate eligibility criteria that considers survivability beyond the acute COVID-related event.**
9. The Triage Protocol must provide clear and specific guidance and **direction as to how random selection should be carried out.**

ARCH Response to Triage Protocol #2 (July 2020)

10. The Triage Protocol must include an **individual dispute resolution process** to ensure fairness, accountability, and due process.
11. The Triage Protocol must include a section dedicated to providing guidance and direction on the **duty to accommodate**.

What about Alberta?

- »» Where are we situated on the Canadian map of pandemic ableism?

A Troubling Lack of Transparency

- ▶ It is virtually impossible for someone without an Alberta Health Services Digital ID to access Alberta's Critical Care Triage Protocol.
- ▶ Such a lack of transparency is highly problematic in that it effectively stifles public dialogue around this issue, while seriously undermining the trust of vulnerable populations, such as people with disabilities, in the healthcare system.

COMMENTARY ■ HEALTH SERVICES

Optimizing provision of extracorporeal life support during the COVID-19 pandemic: practical considerations for Canadian jurisdictions

Ken Kuljit S. Parhar MD MSc, Laurance Lequier MD, Jaime Blackwood MD, Danny J. Zuege MD MSc, Gurmeet Singh MD MSc

■ Cite as: *CMAJ* 2020 April 6;192:E372-4. doi: 10.1503/cmaj.200448; early-released March 26, 2020

Parhar et al describe the development of Alberta's Critical Care Triage Protocols in the following terms:

- ▶ In Alberta, a sub-group of the provincial Critical Care Strategic Clinical Network's COVID-19 Pandemic Planning Group has proposed [Extracorporeal Life Support] ECLS referral based on a principled approach

Pandemic Ethics

- ▶ Pandemic ethics usually apply utilitarian principles, with application, redirection or restriction of resources to those who can benefit most. Patients with the best perceived prognosis tend to be prioritized, necessitating more restrictive “entry” criteria and adaptation of usual “exit” criteria. Waning capacity of ECLS through attrition of staff or supplies or overutilization related to high demand should also be considered.

Alberta's 4-Level System for Triageing ECLS Services

- ▶ **Level 1:** A state of sustainable operations.
- ▶ **Level 2:** A state of increased strain on resources that will restrict an expanded group of patients from accessing ECLS.
- ▶ **Level 3:** A high strain on resources requiring that ECLS be restricted to only those patients with the highest probability of survival.
- ▶ **Level 4:** An overwhelming demand for critical care resources, in which ECLS services would be suspended to redirect all available critical care resources to other critically ill patients.

Human-and-Disability-Rights Critique Also Applicable to Alberta's Critical Care Triage Protocol

- ▶ Like the first version of Ontario's Protocol, Alberta's Protocol lists the presence of a pre-existing disability as an exclusion criterion for critical care.

Human-and-Disability-Rights Critique Also Applicable to Alberta's Critical Care Triage Protocol

- ▶ Parhar and colleagues explicitly situate the development of Alberta's Protocol within an established convention of basing "pandemic ethics" on utilitarian principles which dictate the "application, redirection or restriction of resources to those who can benefit most."

Human-and-Disability-Rights Critique Also Applicable to Alberta's Critical Care Triage Protocol

- ▶ Such privileging of patients based on which ones have the “best *perceived* prognosis” is clearly rooted in ableist notions of disability as always, automatically being detrimental to a person's quality of life, and consequently results in people with disabilities being summarily denied critical care.

Duty to Accommodate – The Ethical Imperative for a Human-and-Disability-Rights-Based Approach to Healthcare Policies and Protocols related to COVID-19 and Beyond

- ▶ We are thus left with the question: What viable alternative is there to the utilitarian and ableist pandemic policies and protocols which have been implemented across Canada, and around the world during this COVID-19 pandemic?

Duty to Accommodate – The Ethical Imperative for a Human-and-Disability-Rights-Based Approach to Healthcare Policies and Protocols related to COVID-19 and Beyond

- ▶ It seems to me that the clear evidence of the pervasiveness of ableism throughout Canadian society in general, and within Canada's healthcare system in particular, that has been made manifest during this pandemic can be ameliorated only by a wholesale shift from an ethical framework that is based on utilitarianism, to an ethical framework that is based on human rights in general, and disability rights in particular.

The Link Between Ethics and Human Rights

- ▶ Anthropologist Mark Goodale conceptualizes human rights as “a particular ethical theory constituted through social practice.”

The Link Between Ethics and Human Rights

- ▶ “The central assumption of the rights paradigm is that every person can make certain claims based solely on their humanness ... Taken literally, a right to health makes little sense: no government can guarantee the health of a citizen. The right to health, however, is actually shorthand in rights discourse for the more complex terminology of international treaties and documents. Health within the rights paradigm is an entitlement, a very different concept from health as a commodity. As a right, individuals can lay claim to it, which, symbolically at least, has great significance. Governments ratifying UN agreements with articles pertaining to health are obliged to report on actions taken to improve the health of their people.” – Wendy Austen, Ph.D.

Disability Rights & Disability Ethics

- ▶ Disability rights is a subset of human rights.
- ▶ Jerry Alan Winter notes that, “The disability rights movement, while by no means a monolith, is one whose slogan [is] ‘Nothing about us without us.’”

Disability Rights & Disability Ethics

- ▶ Having its roots in the disability–rights movement, disability ethics, likewise, is centered around the tenet that the perspectives and lived experiences of people with disabilities should always be central to discussions and debates about ethical issues involving disability and people with disabilities.

A Human-and-Disability-Rights-Based Ethical Framework

- ▶ A human-and-disability-rights-based ethical framework thus takes as its core principle the equal worth and worthiness of all human life, regardless of the presence or absence of disability.

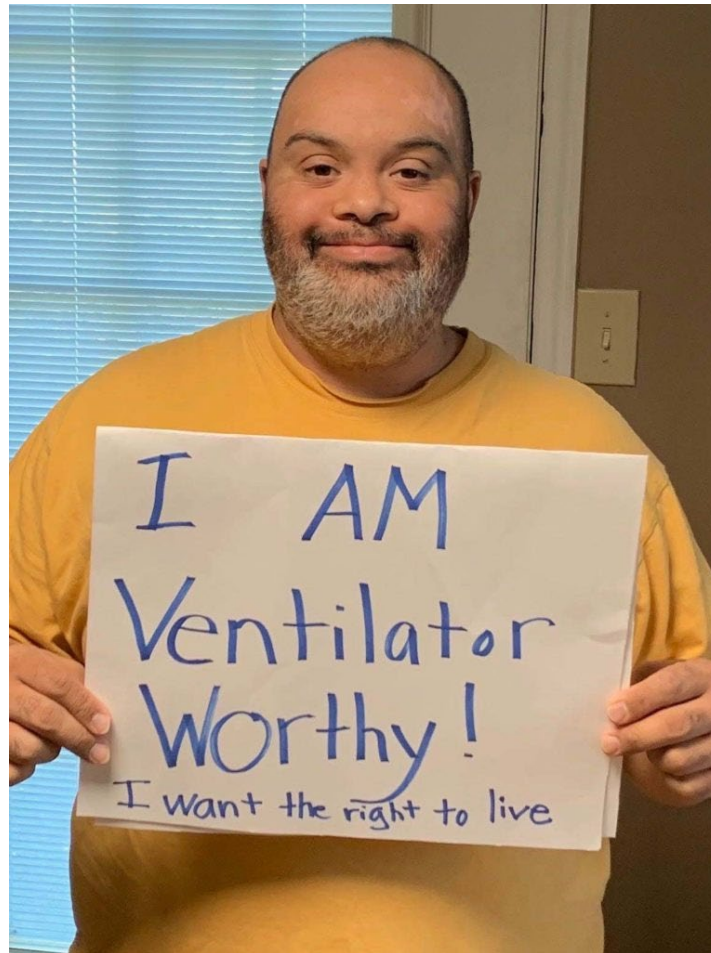
A Human-and-Disability-Rights-Based Ethical Framework

- ▶ Eva Kittay has suggested that a contributing factor to the devaluing and disparagement of disability is a failure to practice what she calls *epistemic modesty*, that is, knowing what one does not know.

A Human-and-Disability-Rights-Based Ethical Framework

- ▶ Only through the practice of epistemic modesty can clinicians ensure that their treatment decisions are not influenced by latent ableism in their assumptions about the quality of life experienced by people with disabilities.

Who Gets the Ventilator???



7 Guidelines for ensuring that Pandemic Medical Policies and Protocols align with Human Rights and Disability Ethics Principles

1. **Non-Discrimination and Equity** must become the cardinal ethical principles on which *all* healthcare policies and practices are based.
2. **Healthcare policies which directly impact marginalized populations must be clear**, in terms of being easy to understand, **and transparent**, in terms of being readily available to the public.

7 Guidelines for ensuring that Pandemic Medical Policies and Protocols align with Human Rights and Disability Ethics Principles

- 3. Critical Care Triage Protocols must not rely on medical utility as a central guiding principle.** The adoption of medical utility as a central guiding principle for critical care triage protocols leads to adverse consequences for persons with disabilities, and fails to consider systemic health discrepancies.

7 Guidelines for ensuring that Pandemic Medical Policies and Protocols align with Human Rights and Disability Ethics Principles

- 4. Critical Care Triage Protocols must not rely on the Clinical Frailty Scale in any capacity.**
- 5. Policy and protocol frameworks must shift away from a focus on the intention not to discriminate to whether adverse impact (discrimination) flows from the policy and/or protocol.**

7 Guidelines for ensuring that Pandemic Medical Policies and Protocols align with Human Rights and Disability Ethics Principles

- 6. Critical Care Triage Protocols must eliminate eligibility criteria that considers survivability beyond the acute COVID-related event.**
- 7. Critical Care Triage Protocols must include a section dedicated to providing guidance and direction on the duty to accommodate a patient's disability-related needs.**

THANK YOU
FOR YOUR ATTENTION!!

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