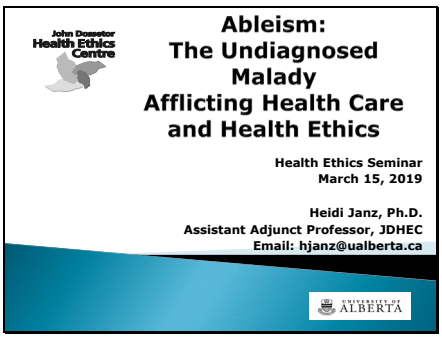
Slide 1



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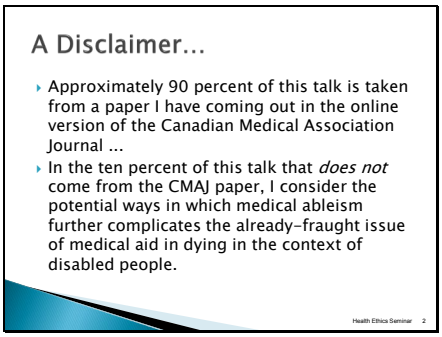

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Slide 4

Galli et al 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." They further contend that, "Immediately, and from early life and thereafter, people perceive individuals with disability as, vulnerable, and of low competence, and, accordingly, treat members of this group differently."

Slide 5

Defining Ableism

- Disability scholar, Veronica Chouinard, defines ableism as, "ideas, practices, institutions and social relations that presume ablebodiedness, and by so doing, construct persons with disabilities as marginalized, and largely invisible, others."

-- Chouinard,1997

Slide 6

- "Ableism and preference of certain abilities has been rampant throughout history. Ableism shaped and continues to shape areas such as human security, social cohesion, social policies, relationships among social groups, individuals and countries, humans and non-humans, and humans and their environment. Ableism is one of the most societally entrenched and accepted isms."

-- Gregor Wolbring, 2008

Slide 7

- "From the moment a child is born, he or she emerges into a world where he or she receives messages that to be disabled is to be less than, a world where disability may be tolerated but in the Final instance, is inherently negative. We are all, regardless of our status, shaped and formed by the politics of ableism."

  -- Fiona Kumari Campbell, 2009

Slide 8

Impacts of Ableism on Canadians with Disabilities

- In 2017, persons with disabilities faced lower employment rates, particularly for Canadians with very severe disabilities, and those with lower levels of education.
- About 59% of working-age adults with disabilities were employed compared with around 80% of those without disabilities.

Slide 9

Impacts of Ableism on Canadians with Disabilities

- However, as severity of disability increased, the percentage of those employed fell from 76% among those with mild disabilities to 31% among those with very severe disabilities.
- In addition, among working age adults, 28% of those with more severe disabilities were living below Canada's official poverty line (based on the Market Basket Measure), compared with 14% of those with milder disabilities and 10% of those without disabilities.

Slide 10

No Place Like Home

- In September 2014, the CBC Radio Program, The Current, reported that, in Ontario alone, 5,338 people with disabilities and under age 65 were admitted to nursing homes between 2008 and 2012. Recently released data from the 2016 Census indicates that there were 11,320 people with disabilities and under age 65 living in nursing homes in 2015.

Slide 11

No Place Like Home

- Alberta Health Services reports that 1,792 people with disabilities aged 19-64 were living in long-term care facilities in 2015-16. This means that, in 2015-16, approximately 13% of beds in Alberta nursing homes were occupied by people with disabilities under age 65. That's an increase of 3% in 12 years for Alberta.

Slide 12

Ableism grounded in a Biomedical Understanding of Disability

- Campbell defines ableism as, "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human."

Slide 13

Ableism grounded in a Biomedical Understanding of Disability

- Campbell delineates an inherent link between this deficit-based construction of disability and a "biomedicalist stance," which, since the Age of Reason, has played a critical intervening role in the lives of people with disability and people with anomalous bodies or mentalities.

Slide 14

Medicine: the Primary Medium for Determining the Meaning of Disability

- Medicine has operated as the primary paradigm not only for the treatment of disabled bodies but has also shaped the way decision makers, legislators, families and society in general *think* about and *sense* disability.

Slide 15

Problems with "Quality of Life"

- Conflation of health with function
- 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.

Slide 16

The Ableist Conflation

- Reynolds explains that, "Wherever operative, the ableist conflation flattens communication about disability to communication about pain, suffering, hardship, disadvantage, morbidity, and mortality."

Slide 17

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, literally, goes without saying."
- Within this milieu of "common sense" ableism, people with disabilities are routinely made vulnerable in medical settings.

Slide 18

The Vulnerability of People with Disabilities in Medical Settings

- Studies have consistently shown that the Emergency Department environment can be stressful for people with developmental disabilities and/or communication disabilities, both because deficits associated with these conditions hamper these individuals' ability to communicate their concerns, and because staff often do not have the skills needed to work with them.

Slide 19

The Vulnerability of People with Disabilities in Medical Settings

- "Common sense" ableism in Medicine very often results in the application of a utilitarian approach to defining, extraordinary, heroic, and, futile, measures which may be employed to preserve or prolong human life.

Slide 20

The Vulnerability of People with Disabilities in Medical Settings

- The danger that this poses for people with disabilities entering the Medical realm is that things which are considered routine parts of daily living within the disability community, such as the use of feeding-tubes and respirators, suddenly become indicators of an unacceptably low quality of life.

Slide 21

MAiD Complicated by Ableism

- The ubiquity of ableism thus produces a widespread tendency among physicians to equate the presence of disability with a low quality of life that is equivalent to the quality of life experienced by a person who is at the end of life.

Slide 22

MAiD Complicated by Ableism

- The potential harm that this particular aspect of medical ableism poses for Canadians with disabilities has, arguably, increased substantively since the legalization of Medical Assistance in Dying (MAiD) in 2015.

Slide 23

The Case of Candace Lewis

Slide 24

MAiD Complicated by Ableism

- Given the prevalence of ableism, in Canadian society generally, and within health care and health ethics in particular, it is highly probable that the removal of "reasonably foreseeable" natural death as a limiting eligibility criterion for the provision of MAiD will lead to the presence of disability, in and of itself, becoming legitimized as a criterion for MAiD eligibility.

Slide 25

MAiD Complicated by Ableism

- The law currently governing MAiD stipulates that, in order to qualify for MAiD, a person must have a "grievous and irremediable" medical condition, and his/her natural death must be "reasonably foreseeable." There are currently, however, a number of court challenges to the criterion of "reasonably foreseeable" natural death as a limiting requirement for MAiD either underway or pending.

Slide 26

The Case of Roger Foley

Slide 27

Ableism Remains Largely Unrecognized & Unacknowledged

- Council of Canadian Academies Expert Panel Reports on Medical Aid in Dying:
  - People with disabilities and their families have reported, for many years, that the healthcare system makes negative assumptions about the quality of their lives; some health professionals believe life with extensive disabilities is not worth living. The need for improved health equity is a fundamental issue in Canada, increasingly enshrined in provincial and territorial legislation. Improving health equity allows people to achieve their full health potential by removing preventable and avoidable systemic conditions that constrain life choices, including choices at the end of life.

Slide 28

Best Practice for Treating Medical Ableism

- The introduction and increased inclusion of the perspectives of people with disabilities into medical and bioethical curricula
- Joseph Stramondo argues that "the social identity of disability can structure personal experience so that an individual more easily perceives and reasons about the morally salient features of a situation in which one is trying to protect a disabled person's autonomy in a context of ableist structural oppression."

Slide 29

Best Practice for Treating Medical Ableism

- Tom Shakespeare contends, "undoubtedly, an immersion in the personal testimonies of disabled people and in the empirical evidence of their lives would challenge dominant tragedy tropes and hugely improve the understanding of nondisabled bioethicists."

Slide 30

- THANK YOU!
- QUESTIONS?

Slide 31

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