

## How the Mantra of Informed Consent in the Canadian Assisted Dying Debate Obscures Somatic Oppression

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Jonas-Sébastien Beaudry, *Somatic Oppression and Relational Autonomy: Revisiting Medical Aid in Dying through a Feminist Lens*, 52 *U.B.C. L. Rev.* 241 (2020), available at [SSRN](#).

In 2015, Canada's Supreme Court ruled that an absolute prohibition on physician assisted suicide and euthanasia violated the right to life, liberty and security of the person. It did not endorse a full-fledged constitutional right to what has since been termed in Canada 'medical assistance in dying' [hereafter MAID], explicitly limiting its ruling to the circumstances of the plaintiff, a person approaching her natural death due to a fatal neurological disease (Amyotrophic lateral sclerosis). It also suspended its declaration of invalidity for one year, inviting Canada's parliament to develop a 'stringent regulatory regime' and made other statements that left room for lawmakers to design specific access criteria. Yet, the constitutional rights basis of its ruling and parameters it set out in its *ratio decidendi* fuelled a seemingly irresistible rhetoric around the existence of a broad constitutional right to MAID.

This rhetoric found its culmination in a recent bill, which expanded MAID outside an already flexible end of life context. During parliamentary hearings on the new law, [about all major disability rights organizations](#), and three [United Nations Special Rapporteurs](#), warned that the new law, which creates, exclusively for people with disabilities, access to MAID outside the end-of-life context, was stigmatizing and discriminatory. [Some academic commentators expressed dismay](#) about how Canadian feminist scholars jumped on the bandwagon of atomistic autonomy-based rhetoric and failed to account for the complexity of end-of-life decision-making in the context of a seriously constrained health care and social support system. Daryl Pullman, invoking Carol Gilligan, argued for the need to hear from a ["different voice of care"](#). McGill University's professor Jonas Beaudry recently provided such a different voice in Canadian legal scholarship with a sophisticated analysis of the country's MAID debate through a relational theory and disability rights focused lens.

In *Somatic Oppression and Relational Autonomy*, Beaudry puts forward that most Canadian arguments around Medical Assistance in Dying ignore how ableist, ageist and 'diseasist' attitudes can lead to an internalized form of oppression that undermines the autonomy of people with disabilities in their decision making with respect to requests for termination of their life. The paper follows an earlier MAID-focused publication in which Beaudry urged the Canadian Supreme Court, which has in recent years increasingly interpreted even socio-economic rights from a more individualistic angle, to embrace a concept of autonomy that takes stock of our embeddedness in a larger social, cultural and economic context.

With extensive references to relational, feminist, and disability theory, Beaudry puts forward a concept of autonomy that goes beyond the mantra of choice as expressed through "informed consent"; a mantra that dominates Canadian health law and bioethics discourse around MAID and has been strikingly present in Canadian case-law that undergirds the country's legal expansion of MAID. He particularly builds on Diana Meyers' procedural concept of autonomy to explore how factors of oppression can compromise the relational competency to construct one's authentic self, and how that concretely plays out for people with disabilities in the context of MAID. Beaudry adds to Meyers' key components of autonomy—the ability to self-discover, self-define, and self-direct—the notion that autonomy as relational competency requires a sufficient range of options.

After laying out this theoretical basis, the paper analyzes in detail how societal attitudes towards disability, ageing and struggling with illness concretely interfere with people's ability to make autonomous decisions, and particularly so in

the context of a seriously constrained health care context. Beaudry's rich tapestry of how somatic oppression interferes with autonomy finds inspiration in disability literature, but he also discusses evidence of MAID practices in other liberal MAID regimes. Having followed closely the media reporting and having participated actively in Canadian parliamentary hearings on MAID legalization, I find his discussion of how internalizations of shame, disgust, and fear of becoming a dependent self and a burden to others, can contribute to somatic oppression and may fuel demand for MAID particularly compelling. During recent parliamentary hearings, for example, one parliamentarian called for a broadening of MAID with vivid descriptions of what she termed the 'indignity' of incontinency, loss of self-control and pain. Such declarations happened in sessions where other (disabled) Canadians were testifying about the stigmatizing, ableist nature of references to 'loss of dignity' in discourses about what for many is an inevitable component of their daily life. The first official report of Canada's 5 year of MAID practice, which came out after Beaudry's article was published, also confirms explicitly that many people who died by MAID in Canada experienced some of the factors he discusses, such as fear of being a burden to others, loneliness, and an inability to participate in meaningful activities, as key components of their 'unbearable suffering.' Beaudry's analysis should inspire others to concretely document how these concerns are already playing out in practice.

Beaudry concludes his analysis with an agenda for further research and policy work, which should focus in his view on promoting 'social aid in living' and 'dignity in life' for persons with disability. He acknowledges that convincing courts, legislators, and legal scholars to embrace the complexity of how people make health care decisions in the face of oppression, cultural harms, and social inequality, will be an uphill battle. The bright line offered by an atomistic informed consent model, supposedly protected by procedural rituals of health care professionals, offers seemingly easy and pragmatic solutions, which policy makers find uniquely appealing and which dominates our legal discourse. But he puts forward that his approach, which calls for shifting from discourses about safeguards to developing substantive support measures to counter oppression, should be broadly acceptable as it "need not be interpreted as a justification for banning MAiD or directly negating individual preferences in a way that would raise a charge of paternalism."

With this last point, Beaudry may in my view be looking too much for a reconciliation of a disability and feminist critique of MAID with the dogmatic embracing in Canada of open-ended life-termination by choice. Beaudry's analysis should, so it seems to me, also inspire a questioning of the expressivist impact of a legislative endorsement of the medical profession's role in actively ending the lives of people with disabilities who are otherwise not close to death, based on inherently complex concepts of autonomy and suffering. Canadian law now explicitly endorses in legislation the perception (a self-perception but one which clearly—as convincingly argued by Beaudry—is influenced by context and other-perception) that a life with disability is more likely unbearable, lacking in dignity, and without further purpose, than the lives of others.

Beaudry's argument that 'informed consent' procedures and current safeguards in Canadian MAID law do not address the much more fundamental issue of somatic oppression and its impact on autonomy is spot on. But particularly those reading his insightful analysis from outside the Canadian context should ask whether the legalization of the practice of state-supported, medical profession organized ending of life of people with disabilities isn't in and of itself a form of state-supported oppression which risks fundamentally undermining their autonomy, and above all, constitutes an immediate threat to their lives.

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