

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

Heidi Janz, Ph.D.

Associate Adjunct Professor, John Dossetor Health Ethics Centre University of Alberta

hjanz [at] ualberta [dot] ca

Two years ago, I was one of the Canadian disability rights advocates who testified before the Parliamentary Justice Committee studying Bill C-7, which would expand eligibility for Medical Assistance in Dying to people with illnesses and disabilities whose death is not reasonably foreseeable. We testified that, if this expansion of eligibility for MAID went ahead in a Canadian society plagued by systemic ableism, death by MAID would quickly become a socially accepted path of least resistance for ill and disabled people who are unable to access sufficient supports to live self-determined lives with dignity in the community. Sadly, our warnings were met with a collective shrug, and Bill C-7 was passed into law. Today, I will offer evidence that Bill C-7's expansion of eligibility for MAID is, in fact, resulting in increasing numbers of ill and disabled people turning to MAID as their only alternative to abject poverty and/or incarceration in a long-term care facility. My hope, faint though it may be, is that you, as Canada's policymakers, will finally recognize that Canada's current MAID regime is, in fact, eugenics disguised as autonomy, and take bold and courageous action to stop the injustice.

A Hobson's choice is defined as a situation in which it seems that you can choose between different things or actions, but there is really only one thing that you can take or do.¹ Contrary to the claims of some MAID enthusiasts who have testified before this committee

¹ Hobson's Choice. Cambridge Advanced Learner's Dictionary & Thesaurus. https://dictionary.cambridge.org/dictionary/english/hobson-s-choice.

(think Dr. James Downar), in the year-and-a-half since Bill C-7 was passed, we have seen death by MAID become a Hobson's choice for growing numbers of ill and disabled Canadians. Among these are:

Chris Gladders, age 35, who died by MAID in January 2021. He was battling Fabry's disease, a genetic condition which affects the body's ability to break down a specific fatty acid and causes a number of side-effects. He had two daughters, Hailee, 13, and Savannah, 5. He lived in a long-term care facility in Niagara, Ontario. His brother reported that at the time of his assisted death, "The bedding hadn't been changed for weeks. There was feces on the bed. There was urine on the bed. There was urine and feces on the floor, the room was absolutely disgusting." And that the day before his death "He pulled the call bell beside his bed. I was on the phone with him for 40 minutes and nobody answered that bell. That was his last night."²

Equally disturbing is the case of "Sophia."

"Sophia" was the preferred pseudonym of a 51-year-old Ontario woman who had Multiple Chemical Sensitivities, a chronic condition. She underwent a medically-assisted death after her desperate search for affordable housing free of cigarette smoke and chemical cleaners failed. "The government sees me as expendable trash, a complainer, useless and a pain in the ass," "Sophia" said in a video filmed on Feb. 14, 2022, eight days before her death. She died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. She also left behind letters showing a desperate two-year search for help, in which she begs local, provincial and federal officials for assistance in finding a home away from

² Bobby Hristova, "Niagara MPP calls for province to take over 'disgusting' Greycliff Manor after 35-year-old dies | CBC News", (29 January 2021), online: *CBC* https://www.cbc.ca/news/canada/hamilton/greycliff-manor-covid19-1.5891730>.

the smoke and chemicals wafting through her apartment. Four Toronto doctors were aware of Sophia's case, and they also wrote to federal housing and disability government officials on her behalf. In that letter the doctors confirmed that her symptoms improved in cleaner air environments and asked for help to find or build a chemical-free residence. "We physicians find it UNCONSCIONABLE that no other solution is proposed to this situation other than medical assistance in dying," they wrote.³

A personal postscript to Sophia's story. Taped to the wall by my computer at home is a letter that Sophia wrote to me three days before her death by MAID. In the letter, she thanked me for my efforts to advocate on her behalf, apologized that she did not have the strength to continue to fight, and asked that I continue to tell her story in the hopes that, one day, people with disabilities in Canada who find themselves in situations similar to hers will not be driven to seek MAID as their only option when they no longer have the strength to fight for their right to live. I keep Sophia's card where I can see it every day to remind myself of what, and who, is at stake in the ongoing disability-rights advocacy work to stop the so-called "right to die" from nullifying people with disabilities' right to life.

And finally, there is the equally troubling and tragic story of Sathya Kovak.

Sathya Dhara Kovak was a Winnipeg woman who died by MAID on October 3, 2022. Kovac lived with amyotrophic lateral sclerosis (ALS). Her condition was worsening, but she felt she had more life to live — just not enough home care support to do so. "Ultimately it was not a genetic disease that took me out, it was a system," Kovac wrote in an obituary to loved ones. Her

³ Avis Favaro, "Woman with chemical sensitivities chose medically-assisted death after failed bid to get better housing", (13 April 2022), online: *CTVNews* https://www.ctvnews.ca/health/woman-with-chemical-sensitivities-chose-medically-assisted-death-after-failed-bid-to-get-better-housing-1.5860579>.

obituary continues, "There is desperate need for change. That is the sickness that causes so much suffering. Vulnerable people need help to survive. I could have had more time if I had more help."⁴

There, is, indeed a desperate need for change. In the words of Canadian disability scholar, Jerome Bickenbach, when an individual chooses death as the only viable way to escape an intolerable situation partly brought on by the social environment, it seems "perverse and unfair to say that this is an expression of self-determination or autonomy." It is incumbent upon you, as Canadian policymakers, to take courageous action to correct the perversion of justice that is Canada's current MAID regime.

⁴ "KOVAC SATHYA - Obituaries - Winnipeg Free Press Passages", online: <https://passages.winnipegfreepress.com/passage-details/id-311052/KOVAC_SATHYA?fbclid=IwAR3g9BBlzc5CqpU8AF93Zu346irJ-PiNBbOqVg0Ut44yV8tvN8D1woRi25A>.