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In 2019, 419 people died using medical assistance in dying in Canada's residential care facilities. (Health Canada 43). In 2020, 522 people died using medical assistance in dying in Canada's residential care facilities (Health Canada 37). In 2021, 752 people died using medical assistance in dying in Canada's residential care facilities. (Health Canada 46). In 2022, 1201 died using medical assistance in dying in Canada's residential care facilities. (Health Canada 54).

Residential care facilities, are known by the *United Nations Convention on the Rights of Persons with Disabilities* as disability institutions.[1] Institutions for disabled people are an ongoing phenomenon stretching back more than a century and a half in Canada (Fritsch et al. 4).[2] Institutions are defined by the *United Nations Committee on the Rights of Persons with Disabilities* by their elements, which together create a "place in which people do not have, or are

[1] In 2009/2010 Statistics Canada recorded 35,078 residents in residential care facilities for people with mental disorders. In 2021, the population of residents in facilities for mental disorders is 57,230 residents. These are aggregate numbers for all residential care facilities for all mental disorders, including mental health & substance use facilities, and developmental disability facilities, as Statistics Canada does not publish disaggregated data on the Residential Care Facility Survey. Presently, there are 542, 500 people with disabilities living in residential care and nursing facilities in Canada. Including emergency shelters, residential services, and correctional facilities, there are 620,680 people living in congregate settings in Canada.

[2] See for instance: Burghardt, M. C. (2018). Broken: Institutions, families, and the construction of intellectual disability (Vol. 50). McGill-Queens University Press.; Chapman, C. (2014). Five Centuries' Material Reforms and Ethical Reformulations. In L. Ben-Moshe, C. Chapman, & A. C. Carey (Eds.), *Disability Incarcerated*. Palgrave Macmillan.; Hansen, N., Hanes, R., & Driedger, D. (2018). *Untold Stories: A Canadian Disability History Reade*r. Canadian Scholars.

not allowed to exercise, control over their lives and their day-to-day decisions" (Joint Task Force on Deinstitutionalization; UNCRPD 3).

In many of Canada's institutions access to pleasure, leisure or pain management are limited by funding limitations, and institutional structures (Fritsch 36). Instead, institutions like prisons, long-term care homes and psychiatric institutions, maintain conditions of neglect, isolation, and such disregard for individual autonomy that it produces depression, and suicidality in people both inside the institution, and those who fear it in their future (Chapman et al. 18**)**.

Jean Truchon's testimony to the Supreme Court of Canada in his challenge to the Medical Assistance in Dying laws was clear—he would rather die than live in an institution.

Nancy Russel, a 90-year-old used MAiD as a result of the isolation her COVID-19 pandemic forced her to endure (Favaro et al.). Meanwhile, 39-year-old Michal Kaliszan is currently raising money for home care notes that for him, "letting myself be admitted is akin to a death sentence and would be a grave dishonour to the sacrifices my parents went through to build me a life in Canada. I refuse to go and will choose euthanasia over being institutionalized in LTC" (Kaliszan).

Decades of class action settlements, years of inquests, archives, interviews with survivors are all replete with stories of death–of friends, roommates, and fellow inmates–all disabled people who died by suicide, who hung themselves from the rafters (Williston 12; Linton 34**)**, jumped from water towers (Linton *23:00-25:00***)**, who died by suicide years after escaping the institution but still haunted by their experiences inside it. For many years, these suicides were a catalyst for great social change, resulting in government commissions and inquiries into the deaths (Williston 3).

Institutions for disabled people have long been associated with death. Historically, deaths have been one of few windows into institutions.

Sometimes, these are murky windows—as was the case of the Huronia Regional Centre. In Orillia, at least 1,379 disabled people were buried on the grounds, in some instances without markers or names (Alamenciak A3).

But the view into the institution no matter how murky, is a view into austerity—privatization yielding bed sores, neglect, forced feeding. We had a view inside the institutions where disabled people live with the confluence of the expansion of MAiD with Chris Gladder's death in his retirement home before you passed Track 2 changes **(**Polewski). In the institution where he was forced to live, feces stained the floor, and instead of cleaning it up, you made changes to MAiD to expand Track 2.

Between March 2020 and May 2023, 22 142 people have died from COVID-19 infection in Canada's residential care facilities (Loreto).

Disabled people are dying en masse in institutions they had been fighting to leave. And today, the deaths within institutions have become so frequent, that we are always haunted by the possibility of loss.

In BC, Dulcie McCallum highlighted of the Woodlands "many examples of unexpected deaths occurring in questionable circumstances," which "arose because of serious overcrowding, very poor staff-resident ratio (e.g., 6 staff to 72 residents on one ward), poorly equipped wards (e.g., inoperable, poorly situated or out-of-date suction equipment) and lack of staff training for the medical challenges facing many of the residents" (McCullum 22-23).

However, as of 1978,[3] Statistics Canada no longer collects national institutional death data, and instead provinces may collect it individually (Wolf & Wright**).** As a result of these changes, data on institutional deaths are limited.

As a result of these data gaps, research is limited by provincial reporting mechanisms. This is a partial snapshot:

Between 2008-2014, in Ontario's developmental disability group homes 1,163 disabled residents died (Auditor General of Ontario). In psychiatric institutions, in Canada just 7 years, 300 disabled people died in psychiatric institutions by suicide (Burns-Pieper & Newman). In prisons, where the population is disproportionately disabled mortality rates are significantly higher than the general population, particularly in relation to suicide (Wittingham et al.). More specifically, prisons see "[s]uicide rates of 70 per 100 000 in federal custody and 43 per 100 000 in provincial custody compared with the overall Canadian rate of 10.2 per 100 000, and homicide rates of 22 per 100 000 in federal custody and 2.3 per 100 000 in provincial custody compared with the overall Canadian rate of 1.6 per 100 000" (Kouyoumdjian et al. 217).

In a ten-year period from 2001-2002 to 2010-2011, 530 incarcerated people died, of which 92 were from suicides. In 2021, 219 disabled people, who were not at the end of their lives, ended their lives through medical assistance in dying (Health Canada).

Last week, Honourable Minister David Lametti expressed the intention of Track 2 MAiD, necessary he says because disabled people are unable to complete suicides.

[3] At the time the data collection ceased, the increased mortality rates, where the average life expectancy was 55 years of age for males, and 50 for females. Compared to the general population, which was 78 for females and 71 for males.

> Remember that suicide generally is available to people. This is a group within the population who, for physical reasons and possibly mental reasons, can't make that choice themselves to do it themselves. And, ultimately, this provides a more humane way for them to make a decision they otherwise could have made, if they were able in some other way. (qtd in Raj**).**

As a researcher of institutions, the fallacy of this argument is troubling—in institutions disabled people have higher than average mortality rates, higher than average rates of suicide, higher than average exposure to infectious disease.

So, if not practicality, then we must look at the political economy, for the timing of these decisions. I borrow the words of Marta Russel two decades ago, in wondering, why now, with the increase of pandemics and incurable illnesses like COVID and long COVID? Why now, with pandemic health care rationing, and with health care under the budget ax?

The expansion of MAiD then must be viewed within the "context of this economic order which is eviscerating the social contract by encouraging government to retreat from its responsibilities to the public's welfare. You feel generous to provide mercy from the austerity that you've designed" (Russell).

To all of you, disabled people do not need your help to die. You have been killing us for years. We need your help to get out of the institution you trapped us in. The only safeguard for MAiD is foreseeable death.

Do not be mistaken, this provision of death under Track 2 MAiD is eugenics, and it must be repealed as soon as possible.

References

Alamenciak, Tim. "Remembering Huronia's Forgotten Lives; Some 1,440 Residents of Notorious Institution Were Buried in Unmarked Graves. A Group of Survivors Wants to Change That." *Toronto Star*, 2014.

Chapman, Chris, et al. "Reconsidering Confinement: Interlocking Locations and Logics of Incarceration." *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, Plagrave Macmillan, 2014.

Favaro, Avis, et al. "Facing Another Retirement Home Lockdown, 90-Year-Old Chooses Medically Assisted Death." *CTV News*, 19 Nov. 2020,

Fritsch, Kelly. "Gradations of Debility and Capacity: Biocapitalism and the Neoliberalization of Disability Relations." *Canadian Journal of Disability Studies*, vol. 4, no. 2, 2, 2015, pp. 12–48.

Fritsch, Kelly, et al. "Resisting the Criminalization of Disability: Cripping Disability Injustice toward Accessible Decarceral Futures." *Disability Injustice: Confronting Criminalization in Canada*, edited by Kelly Fritsch et al., UBC Press, 2022.

Health Canada. *First Annual Report on Medical Assistance in Dying in Canada, 2019*. annual report, Health Canada. 24 July 2020.

---. *Second Annual Report on Medical Assistance in Dying in Canada 2020*. annual report, Health Canada. 30 June 2021.

---. *Third Annual Report on Medical Assistance in Dying in Canada 2021*. annual report, Health Canada, 26 July 2022.

Joint Task Force on Deinstitutionalization. "Definition of an Institution." *Institution Watch*, https://www.institutionwatch.ca/task-force/definition-of-an-institution/.

Kaliszan, Michal. "Home Care for Michal Kaliszan." *GoFundMe*, 2022, https://www.gofundme.com/f/home-care-for-michal-kaliszan.

Kouyoumdjian, Fiona, et al. "Health Status of Prisoners in Canada." *Canadian Family Physician*, vol. 62, no. 3, Mar. 2016, pp. 215–22.

Linton, Megan. "Class Inaction." *Briarpatch Magazine*, vol. 51, no. 6, Nov. 2022, p. 34, https://briarpatchmagazine.com/articles/view/class-inaction.

Linton, Megan. *The Hellhole from Manitoba: The Manitoba Developmental Centre*. Invisible Institutions. 3.

Loreto, Nora. *Deaths in Residential Care in Canada by Facility*. May 2023.

McCallum, Dulcie. *The Need to Know: Administrative Review of Woodlands Institution*. Administrative review, Ministry of Children and Family Development, Aug. 2001, pp. 1–37.

Office of the Auditor General of Ontario. *2016 Annual Report of the Office of the Auditor General of Ontario*. Office of the Auditor General of Ontario, 2016.

Polewski, Lisa. "Hamilton Man Dies amid 'Disturbing' Living Conditions at Niagara Falls Home, Says Family." *Global News*, Jan. 2021.

Raj, Althia. "Justice Minister David Lametti under Fire for 'Unbelievable' Comparisons between Euthanasia and Suicide." *Toronto Star*, 29 Nov. 2022.

Russell, Marta. "Dollars And Death." *ZNetwork*, 11 May 1999.

"Suicide Watch." *W5*, directed by Annie Burns-Pieper and Kevin Newman, 49.1, CTV, 4 Oct. 2014,

United Nations Committee on the Rights of Persons with Disabilities. *General Comment No.5 on Article 19 - the Right to Live Independently and Be Included in the Community*. General Comment, 5, United Nations Human Rights Office of the High Commission, 27 Oct. 2017.

Whittingham, Lisa, et al. "The Prevalence and Health Status of People with Developmental Disabilities in Provincial Prisons in Ontario, Canada: A Retrospective Cohort Study." *Journal of Applied Research in Intellectual Disabilities*, vol. 33, no. 6, Nov. 2020, pp. 1368–79.

Williston, Walter. *Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario*. Ontario Department of Health, Aug. 1971.

Wolf, L. C., and R. E. Wright. "Changes in Life Expectancy of Mentally Retarded Persons in Canadian Institutions: A 12-Year Comparison." *Journal of Intellectual Disability Research*, vol. 31, no. 1, June 2008, pp. 41–59.

Appendix

Table 1. Congregate Facility Population in 2019

Facility	Resident Population
Community care facilities for the elderly [6233]	251,830
Nursing care facilities [6231]	193,655
Residential developmental handicap, mental health and substance abuse facilities [6232]	57,230
Other residential care facilities [6239]	39,785
Total	**542, 500**