

Disabled People are Dying En Masse in Institutions

In 2019, 419 people died using medical assistance in dying in Canada's residential care facilities.¹

In 2020, 522 people died using medical assistance in dying in Canada's residential care facilities.²

In 2021, 752 people died using medical assistance in dying in Canada's residential care facilities.³

Residential care facilities are also called disability institutions, as per the *United Nations Convention on the Rights of Persons with Disabilities*.⁴ Institutions for disabled people are an ongoing phenomenon stretching back more than a century and a half in Canada.⁵ Institutions are defined by the *United Nations Committee on the Rights of Persons with Disabilities* by their

¹ Canada, H. (2020, July 24). *First Annual Report on Medical Assistance in Dying in Canada, 2019* [Transparency - other].

<https://www.canada.ca/en/health-canada/services/medical-assistance-dying-annual-report-2019.html>

² Canada, H. (2021, June 30). *Second Annual Report on Medical Assistance in Dying in Canada 2020* [Datasets].

<https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html>

³ Canada, H. (2022). *Third annual report on Medical Assistance in Dying in Canada 2021* [Annual report]. Health Canada.

<https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html>

⁴ As of 2022, the size of the population of disabled people living in congregate group settings in Canada is relatively unknown. 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.

Given the presence of disability, institutionalization comprises various residential care facilities—long-term care institutions, children's group homes, hospitals, and emergency shelters. 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.

⁵ 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 Reader*. Canadian Scholars.

elements,⁶ which together create a “place in which people do not have, or are not allowed to exercise, control over their lives and their day-to-day decisions”.⁷

In many of Canada’s institutions access to pleasure⁸, leisure or pain management are limited by funding limitations, and institutional structures. Instead, institutions like prisons, long-term care homes and psychiatric institutions, maintain conditions of neglect⁹, isolation¹⁰, 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.¹¹

People have been clear in their discussions—they 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.¹² 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.”¹³

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

⁶ “such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment.” from United Nations Committee on the Rights of Persons with Disabilities. (2017). *General comment No.5 on Article 19—The right to live independently and be included in the community* (General Comment No. 5). United Nations Human Rights Office of the High Commission.

<https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

⁷ Deinstitutionalization Task Force. (2005). Definition of an Institution. Institution Watch.

<https://www.institutionwatch.ca/task-force/definition-of-an-institution/>

⁸ Lichtenberg, P. A. (2014). Sexuality and Physical Intimacy in Long Term Care. *Occupational Therapy in Health Care*, 28(1), 42–50. <https://doi.org/10.3109/07380577.2013.865858>

⁹ McDonald, L. (2011). Elder Abuse and Neglect in Canada: The Glass is Still Half Full. *Canadian Journal on Aging / La Revue Canadienne Du Vieillessement*, 30(3), 437–465.

<https://doi.org/10.1017/S0714980811000286>

¹⁰ Parkes, D. (2015). Ending the Isolation: An Introduction to the Special Volume on Human Rights and Solitary Confinement. *Canadian Journal of Human Rights*, 4, i–iv.

<https://heinonline.org/HOL/P?h=hein.journals/canajo4&i=1>

¹¹ Hoben, M., Heninger, A., Holroyd-Leduc, J., Knopp-Sihota, J., Estabrooks, C., & Goodarzi, Z. (2019). Depressive symptoms in long term care facilities in Western Canada: A cross sectional study. *BMC Geriatrics*, 19(1), 335–335. <https://doi.org/10.1186/s12877-019-1298-5>

¹² Favaro, A., St. Philip, E., & Jones, A. M. (2020, November 19). Facing another retirement home lockdown, 90-year-old chooses medically assisted death | CTV News. CTV News.

<https://www.ctvnews.ca/health/facing-another-retirement-home-lockdown-90-year-old-chooses-medically-assisted-death-1.5197140?cache=bnbdbzprissrh%3FclipId%3D104070>

¹³ <https://www.gofundme.com/f/home-care-for-michal-kaliszan>

who died by suicide, who hung themselves from the rafters¹⁴, jumped from water towers,¹⁵ who died by suicide years after escaping the institution but still haunted¹⁶ 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.¹⁷

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.¹⁸

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 death¹⁹ in his retirement home before you passed Track 2 changes. 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.

Since March 2020, 21,878 people have died from COVID-19 infection in Canada's residential care facilities.²⁰

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 (2001) highlighted of the Woodlands “many examples of unexpected deaths occurring in questionable circumstances”, which “arose because of serious

¹⁴ Williston, W. (1971). *Present arrangements for the care and supervision of mentally retarded persons in Ontario*. Ontario Department of Health.

<https://www.mcass.gov.on.ca/documents/en/mcass/dshistory/legislation/Williston%20Report.pdf>

¹⁵ Weremy, D. in Linton, M. Manitoba Developmental Centre. (audio documentary). Invisible Institutions. <http://invisibleinstitutions.com/invisible-institutions-podcast-episode-3>

¹⁶ Butler, C. (2021). Victims recall traumatic details of child abuse at CPRI in emotional settlement hearing. *CBC London*. <https://www.cbc.ca/news/canada/london/cpri-class-action-1.6075603>

¹⁷ Williston, W. (1971). *Present arrangements for the care and supervision of mentally retarded persons in Ontario*. Ontario Department of Health.;

Blair, W. R. N. (1969). *Mental health in Alberta: A report on the Alberta Mental Health Study 1968*. Edmonton, Canada : Human Resources Research and Development Executive Council – Government of Alberta <https://www.mcass.gov.on.ca/documents/en/mcass/dshistory/legislation/Williston%20Report.pdf>

¹⁸ Alamenciak, T. (2014). 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*, A3-. <https://search.proquest.com/docview/1640796381?pq-origsite=primo>

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²⁰ Loreto, N. (2022, May). Deaths in Residential Care in Canada by facility. https://docs.google.com/spreadsheets/u/0/d/1M_Rz0jK0vwF9nAozl7aoyLpPU8EA1JEqO6rq0g1iebU/htmlview

overcrowding, very poor staff-resident ratio [for example 6 staff to 72 residents on one ward], poorly equipped wards [for example inoperable, poorly situated or out-of date suction equipment] and lack of staff training for the medical challenges facing many of the residents”.²¹.

However, as of 1978²², “Statistics Canada no longer collected information on deaths of mentally retarded [SIC] persons in institutions for all of Canada. From that date, the collection of these data was the responsibility of the individual provinces”.²³ As a result of these changes, data on institutional deaths are limited. This is a snap shot:

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

Between 2008-2014, in Ontario’s developmental disability group homes 1,163 disabled residents died.²⁴

In psychiatric institutions, in Canada just 7 years, **300 disabled people died in psychiatric institutions by suicide.**²⁵

In prisons, where the population is disproportionately disabled²⁶ mortality rates are significantly higher than the general population, particularly in relation to suicide.²⁷ 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.

²¹ McCullum, D. (2001). The Need to Know Woodlands School Report: An Administrative Review.

²² 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.

²³ Wolf, L. C., & Wright, R. E. (2008). Changes in life expectancy of mentally retarded persons in Canadian institutions: A 12-year comparison. *Journal of Intellectual Disability Research*, 31(1), 41–59. <https://doi.org/10.1111/j.1365-2788.1987.tb01341.x>

²⁴ Office of the Auditor General of Ontario. (2016). 2016 Annual Report of the Office of the Auditor General of Ontario. Office of the Auditor General of Ontario.

²⁵ Burns-Pieper, A., & Newman, K. (2014, October 4). W5 uncovers 300 suicide deaths by patients in Canadian hospitals. CTV News. <https://www.ctvnews.ca/w5/w5-uncovers-300-suicide-deaths-by-patients-in-canadian-hospitals-1.2038520>

²⁶ Whittingham, L., Durbin, A., Lin, E., Matheson, F. I., Volpe, T., Dastoori, P., Calzavara, A., Lunsky, Y., & Kouyoumdjian, F. (2020). 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*, 33(6), 1368–1379. <https://doi.org/10.1111/jar.12757>; Bernier, J. R. (2011). Health status and health services use of female and male prisoners in provincial jail. Atlantic Centre of Excellence for Women’s Health.

²⁷ “suicide 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.”

Last week, Honourable Minister David Lametti²⁸ expressed the intention of Track 2 MAiD, necessary he says because disabled people are unable to complete suicides.

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. (Hon. **Lametti in Raj, 2022**).

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 use 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 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.

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 safe guard 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.

²⁸ Hon. Lametti, as quoted in Raj, A. (2022, November 21). Canada should think twice before expanding MAiD. *Toronto Star*.
<https://www.thestar.com/politics/political-opinion/2022/11/21/why-does-the-trudeau-government-leave-people-no-option-but-to-take-their-own-lives.html>

Appendix

Table 1. Congregate Facility Population

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