

Institutionalization of People Labelled with Intellectual or Developmental Disabilities in Long-Term Care

Prepared by Megan Linton and Kendal David for *Invisible Institutions* and the *Inclusion Canada/ People First of Canada Joint Task Force on Deinstitutionalization*. Design and Layout by Kit Chokly.

EXECUTIVE SUMMARY

- × People labelled with intellectual or developmental disabilities are **reinstitutionalized in long-term care facilities** as a result of shortages in affordable housing, community living services and home care.
- × Long-term care facilities are **highly institutional environments** that prevent personal freedoms, decision making and autonomy for people with disabilities.
- × As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), **Canada has an obligation to ensure that people with disabilities have the freedom to choose their place of residence and live in community.**¹

STATEMENT OF ISSUE

People labelled with intellectual or developmental disabilities (I/DD) are inappropriately institutionalized into long-term care (LTC) facilities. LTC facilities are highly institutional environments where people are unable to choose when or what they eat, how they spend their time, who provides their care, and who they live with. Long-term care violates access to community living and choice for people labelled with I/DD, the federal government has the responsibility to increase investments in affordable housing, home care services, and disability benefits. The right to live in community, as protected by Article 19 of the UNCRPD, is essential for the health, wellbeing and freedom of people labelled with I/DD.

BACKGROUND

LTC facilities are residential institutions, designed to accommodate people with complex support needs who require 24 hour support.²

Thus, the shared characteristic of all LTC facility residents is underlying disability, not age. Over the last 60 years, LTC facilities have been used to institutionalize people labelled with I/DD who require more support.³ Often, they are places of last-resort for people labelled with I/DD, when there are no spaces in developmental services.⁴ The use of LTC facilities for people labelled with I/DD is a result of sustained gaps in: 1) community living services; 2) affordable housing and; 3) home care. In Ontario alone, more than 3,200 people labelled with intellectual or developmental disabilities are institutionalized in LTC facilities.⁵

LTC facilities are overseen by provincial Ministries of Health and Long Term Care and delivered by private and public operators resulting in jurisdictional inconsistencies in service delivery. The 2,076 LTC facilities across Canada accommodate 198,220 people.⁶ Over the past ten years, provinces have made

significant investments in the number of beds and facilities to accommodate the growing aging population. These investments in LTC facilities demonstrate an ongoing reliance on institutional forms of care for persons with disabilities. Conversely, investments in community living services through provincial developmental services have maintained a low-rate of growth.⁷

KEY CONSIDERATIONS

91% of Canadians, and 100% of seniors do not want to live in LTC facilities.⁸

LTC facilities are institutional environments—meals occur at set times with fixed menus, bathing is scheduled, furniture is standardized, recreation is limited and there is a lack of personal privacy. **LTC facilities are in opposition to the freedom of choice, decision-making and autonomy of people with disabilities.** As a signatory to the UNCRPD, the Government of Canada and their provincial counterparts have an obligation to protect and realize the “right for all persons with disabilities to live in community with choices equal to others”.

Currently, people labelled with I/DD do not have adequate choices in where or who they live with. **More than 100,000 Canadians labelled with I/DD do not have access to the affordable housing that they need.**⁹ Affordable housing is a key ingredient to community living for people labelled with I/DD. While waitlists for affordable housing and residential services differ across provinces, there is a national trend of growing waitlists accompanied by low-rates of growth of community living services, see [Table 1](#). Waitlists are indicators for a lack of choice in housing, making it necessary to accept the first placement available, or risk losing their place in the queue. **The use of LTC for people labelled with I/DD is indicative of the gap in available services for people with more complex healthcare needs to live in a community.**

Alongside access to housing, lack of access to home care services increases reliance on institutional forms of care such as LTC facilities.¹⁰ As of 2015/16, at least **433,330 Canadians had unmet home care needs.**¹¹ Home care services are not publicly insured through the *Health Canada Act*, placing the responsibility of home care onto territories, provinces and municipalities, resulting in jurisdictional disparities in service provision. National trends in home care demonstrate an insufficient number of hours, and overall lack of availability of services causing unmet needs.¹²

Amidst the COVID-19 pandemic, 81% of all COVID-19 fatalities in Canada occurred in LTC facilities.¹³ The high rates of COVID-19 deaths co-occurred with an increase in non-COVID-19 deaths associated with staffing and care shortages resulting in neglect, starvation and dehydration.¹⁴ Infection prevention and control strategies in LTC facilities increased experiences of isolation for people with disabilities, as caregivers, family and friends were prohibited or limited from entering LTC facilities. The institutional environments of LTC facilities were exacerbated by the COVID-19 pandemic. Access to caregivers, visitors, and family for LTC residents are essential to interrupting cycles of abuse, resulting in substantial health and safety outcomes.¹⁵ Isolation is further exacerbated by lack of access to the internet within these settings.¹⁶

Long-term care facilities are not designed for people labelled with I/DD, they lack access to recreation, relevant health and social supports, employment, education and volunteer opportunities.¹⁷ The Ministry of Community, Children and Social Services in Ontario responded to the use of LTC facilities for people labelled with I/DD by developing “Long-Term Care Home Access Protocol for Adults with a Developmental Disability”.¹⁸ Guidelines do not address the fundamental institutional environments that underlie LTC facilities.

Table 1: Available waitlists for community living services

Province	Waitlist
British Columbia ¹⁹	2,958
Alberta ²⁰	2,357
Ontario ²¹	15,700
Prince Edward Island ²²	40
Nova Scotia ²³	1,500

RECOMMENDATION

To end the practice of inappropriate institutionalization of people labelled with I/DD in LTC facilities, substantial investments must be made to address barriers to community living across the country. Three primary points of national investment:

1. Investments to expand access to housing for people labelled with I/DD. Canada's National Housing Strategy *A Place to Call Home*, promises a Canadian Housing Benefit to increase access to housing for low-income Canadians. This Benefit must make provisions for people with disabilities in order to address the unique needs and costs of living with a disability.²⁴ Alongside the housing benefit, Indigenous Services Canada must make increased investments in on-reserve housing for First Nations adults with disabilities.²⁵
2. Investments to expand access to home-care services to increase the ability for people with complex disabilities to live in community. Currently home care represents 4% of all national public health care spending, whereas LTC represents nearly 20% of all public health spending.²⁶ Increased investments in home care, to make up 10% of public health spending, would significantly impact access to community based care for Canadians with disabilities.²⁷
3. Investments to end the chronic poverty of people labelled with I/DD through the establishment of a Federal Canada Disability Benefit. Chronic poverty alongside limited access to affordable housing exacerbates demand for institutional services. The Disability Benefit must include people living in LTC facilities who receive provincial allowances as opposed to disability income supports.²⁸

ENDNOTES

- 1 Article 19 of the *United Nations Convention on the Rights of Persons with Disabilities*, enshrines the “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community” <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html>
- 2 Health Canada’s Summary of Long-Term Facility Based Care. <https://www.canada.ca/en/health-canada/services/home-continuing-care/long-term-facilities-based-care.html>
- 3 This is first referenced in the Ontario Legislature February, 11th, 1959 by Honourable M.B. Dymond “Ontario’s Chronic Patients”.
- 4 Lin, E., Balogh, R., Durbin, A., Holder, L., Gupta, N., & Volpe, T. (2019). Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario. Institute for Clinical Evaluative Sciences. <https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>
- 5 *Ibid.*
- 6 Canadian Institute of Health Information’s “Long Term Care Beds Data Table” as of June 10, 2021
- 7 For instance, in both Alberta and Ontario, the rate of growth in community living services in 2019 was just 1%.
- 8 2020 National Institute on Ageing survey <https://www.nia-ryerson.ca/commentary-posts/2020/9/22/almost-100-per-cent-of-older-canadians-surveyed-plan-to-live-independently-in-their-own-homes-but-is-this-even-possible>
- 9 For more information on affordable housing crisis for people labelled with I/DD, see the My Home, My Community, a campaign of Inclusion Canada, People First of Canada and other partners.
- 10 Canadian Healthcare Association. *Home care in Canada: From the margins to the mainstream*. Ottawa: Canadian Healthcare Association, 2009.
- 11 Heather Gilmour, “Unmet home care needs in Canada” Statistics Canada Health Reports. <https://www150.statcan.gc.ca/n1/pub/82-003-x/2018011/article/00002-eng.htm#n3>
- 12 *Ibid.*
- 13 Canadian Institute for Health Information. *Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare With Other Countries?*. Ottawa, ON: CIHI; 2020.
- 14 Canadian Armed Forces Report on LTCF in Ontario, 2020.
- 15 Estabrooks, C. A., Straus, S. E., Flood, C. M., Keefe, J., Armstrong, P., Donner, G. J., Boscart, V., Ducharme, F., Silvius, J. L., & Wolfson, M. C. (2020). Restoring trust: COVID-19 and the future of long-term care in Canada. *FACETS*, 5(1), 651–691. <https://doi.org/10.1139/facets-2020-0056>
- 16 See also: The Digital Divide http://invisibleinstitutions.com/wp-content/uploads/2021/10/InvisibleInstitutions_InternetBrief_FINAL.pdf
- 17 Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2017). The Risk of Re-Institutionalization: Examining Rates of Admission to Long-Term Care Among Adults with Intellectual and Developmental Disabilities Over Time. *Journal of Policy and Practice in Intellectual Disabilities*, 14(4), 293–297. <https://doi.org/10.1111/jppi.12215>
- 18 The guidelines are available at: https://www.mcsc.gov.on.ca/en/mcsc/publications/developmentalServices/ltc_home_guidelines.aspx#part5c
- 19 Issues & Trends from the Executive Director of Community Living Victoria, <https://www.communitylivingvictoria.ca/updates-from-the-ed/june-2011/>
- 20 Inclusion Alberta, Growing Waitlist for Supports for Individuals with Developmental Disabilities. <https://inclusionalberta.org/news/2020/02/26/media-releases/growing-waitlist-for-supports-for-individuals-with-developmental-disabilities/>
- 21 Ontario Developmental Services Housing Task Force. (2018). *Generating Ideas and Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities* [Final Report]. https://cdn.agilitycms.com/partners-for-planning/hf-final-reports-pdfs/HTF%20Final%20Report%202018_Generating%20Ideas_Enabling%20Action_FINAL.pdf
- 22 According to Bill Lawlor, 2019 <https://www.cbc.ca/news/canada/prince-edward-island/pei-36-beds-community-oct-2019-1.5335020>

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- 23 Call to Action: The Road to Inclusion and Equality for People with Disabilities Government Accountability on the Roadmap Choice, Equality and Good Lives in Inclusive Communities <https://www.disabilityrightscoalitionns.ca/wp-content/uploads/2021/07/Disability-Rights-Road-to-Inclusion-2023-FINAL-REPORT.pdf>
- 24 *My Home, My Community* issued a recommendation on the Report—Making the Housing Benefit Work for People with a Disability <https://static1.squarespace.com/static/57f27c992994ca20330b28ff/t/5e84ba5b58dbc43324bad827/1585756763772/MHMC+-+Making+the+Housing+Benefit+Work+-+FINAL.pdf>
- 25 See for instance, the Assembly of First Nations' Report: *First Nations and First Nations Persons with Disabilities Engagement on Federal Accessibility Legislation* March 2017. https://www.afn.ca/uploads/files/afn_fal_report_phase1_eng_-final_.pdf & the 2018 Civil Society Submission to the UN Special Rapporteur on the Right to Housing *Meeting Canada's Obligations to Affordable Housing and Supports for People with Disabilities to Live Independently in the Community: Under Article 19 & 28, Convention on the Rights of Persons with Disabilities* <https://inclusioncanada.ca/wp-content/uploads/2018/05/Canada-Right-to-Housing-for-Persons-with-Disabilities-May-15-2017.pdf>
- 26 Better Home Care in Canada: A National Action Plan, visit <https://cdnhomecare.ca/campaign-better-home-care-in-canada-a-national-action-plan/>
- 27 *Ibid.*
- 28 See Institutional Allowances and the Canadian Disability Benefit Act http://invisibleinstitutions.com/wp-content/uploads/2021/10/InvisibleInstitutions_PNABrief_FINAL.pdf