

Nothing About Us: Addressing Institutional Exclusion from Federal Disability Data

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

- × There has not been a national survey on persons with disabilities who live in institutions for the past 30 years.¹
- × The Census and Canadian Survey on Disability (CSD) excludes people with disabilities living in residential institutions.²
- × Excluding people with disabilities who live in institutions from national and disability-specific data collection makes it difficult to implement evidence-based policy, assess commitments to the United Nations Convention on the Rights of Persons with Disability (UNCRPD) and evaluate contemporary policies.
- × To adequately address these gaps, Statistics Canada should re-implement and modernize the Health and Activity Limitation Survey methodology which collects data from small and medium sized institutions and samples within each large-sized institution as part of the CSD.

STATEMENT OF ISSUE

The last survey of people with disabilities who live in residential institutions was in 1991. Contemporary survey and census exclusions of persons who live in residential institutions create significant data gaps, making it difficult to design and implement evidence-based disability policy. These gaps also make it challenging to assess national and international commitments to human rights for persons with disabilities.³ Addressing the severe data gaps regarding institutionalization in Canada (by, for example, re-implementing and modernizing the Health and Activity Limitation Survey methodology) is critical for the development of evidence-based policies across ministries, including the *Canadian Disability Benefit Act*, and the Disability Inclusion Action Plan.

BACKGROUND

The 1981 United Nations Year of Persons with Disabilities helped to create the first Special Parliamentary Committee on the Disabled and the Handicapped to address the needs of persons with disabilities. The committee released the report, *Obstacles*, with 130 recommendations for the inclusion of persons with disabilities—including the need for greater data collection.⁴ In response, the first survey on disability in Canada was conducted by Statistics Canada in 1986, the Health and Activity Limitation Survey (HALS). The mandate for this survey was to create a national database of people with disabilities, which necessarily included people who live in institutions as respondents, collecting data unique to this sub-population through the Institutional Component (IC).

The methodology of this component of the survey prioritized the voices of people with disabilities through utilizing in-person surveyors to interview persons with disabilities in residential institutions.⁵

The 1991 HALS found that 247,275 people with disabilities live in health-care institutions in Canada and highlighted the disproportionate institutionalization of women and girls with disabilities.⁶ The Institutional Component of the survey was rigorous, comprising nine sections, each with between nine and 89 questions. The IC included all “large” institutions, while conducting samples from “small” and “medium” institutions. The HALS: IC was discontinued in 1991 and renamed to the Participation and Activity Limitations Survey in 2001. Most recently, in 2012, the survey was renamed the Canadian Survey on Disability (CSD), and the methodology was further reformed in 2017. The current CSD methodology “excludes the institutionalized population” and as such, facilitates enormous data gaps in our understanding of disabled life in Canada and hinders the development of evidence-based disability policy.⁷ In order to address this gap, the CSD methodology should re-implement the institutional component from the 1991 HALS.

KEY CONSIDERATIONS

Contemporarily, the only national survey on residential institutions is the Nursing and Residential Care Facility Survey (NRCFS). NRCFS does not gather data from people with disabilities directly as was the case with the HALS methodology; instead, aggregate resident data is provided by health or social services administrators.⁸

There have been significant changes in the institutional landscape since the last national survey in 1991. Over the past 30 years, large institutions for people with intellectual or developmental and psychiatric disabilities have closed in multiple provinces, while

the long-term care system has undergone rapid growth as the senior population has more than tripled in the same period.⁹ These transformations in the sector demonstrate there is a significant population of Canadian citizens who are excluded from national data gathering due to institutionalization.

Further, the COVID-19 pandemic has laid bare the urgency and importance of rigorous disability data collection, especially within residential institutional facilities. More than 18,222 deaths in residential facilities during the COVID-19 pandemic demonstrates the need for up-to-date, rigorous federal data collection regarding persons with disabilities who live in institutional settings. This is particularly the case for people with intellectual or developmental disabilities, who are more than twice as likely to die from COVID-19 than their non-disabled peers.^{10,11} The dearth of federal data and inconsistent provincial public health reporting on institutional outbreaks made it difficult to prioritize vaccines for persons at higher risk for mortality and severe outcomes from COVID-19. Adequate data is necessary for the production of emergency planning policy, particularly in regards to Infection Prevention and Control best practices.

Forthcoming disability policies, including the *Canadian Disability Benefit Act*, and the Disability Inclusion Action Plan cannot adequately meet the needs of all Canadians with disabilities if persons who live in institutional settings are excluded from the data used to guide policy development.

RECOMMENDATION

Mobilizing “Nothing About Us Without Us,” the best practice for including persons with disabilities who live in institutional settings in federal statistical surveys and data, is a methodology which employs direct engagement of persons with disabilities. This is unique from statistical methodologies currently

employed by the federal government, which only record information *about* the persons living in institutional settings. We recommend the re-implementation of the HALS:IC methodology for use with the contemporary CSD to collect data from small and medium sized institutions and samples within each large-sized institution. This includes the collection of data about an individual's financial, health, and basic needs beyond aggregate population numbers.

Re-implementing the HALS:IC methodology would facilitate important new data collection as part of the CSD, facilitating a more comprehensive understanding of disabled life in Canada. Modernizing and mobilizing this existing tool is critical for the development of evidence-based disability policies across ministries. To enable Statistics Canada to conduct this survey, partnerships with Employment and Social Development and Disability Inclusion Canada should be explored.

ENDNOTES

- 1 Elizabeth Lin et al., "Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario" (Institute for Clinical Evaluative Sciences, February 2019), <https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>
- 2 Elisabeth Cloutier, Chantal Grondin, and Amélie Lévesque, "Canadian Survey on Disability, 2017: Concepts and Methods Guide" (Statistics Canada, 2018), ISBN 978-0-660-27535-2, <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018001-eng.htm>
- 3 Article 31 of the United Nations Convention on the Rights of Persons with Disabilities, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>
- 4 Recommendation 113 is "to give a high priority to the development and implementation of long-term strategy which will generate comprehensive data on disabled persons in Canada". Obstacles: Recommendations formulated and progress assessed by the Special Committee on the Disabled and the Handicapped. (1985). Ministry of Supply and Services Canada.
- 5 Statistics Canada, "1991 Health and Activity Limitation Survey: Institutional Component (HALS)" (2006), <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=4732>
- 6 Owen Adams et al., "Profile of Persons with Disabilities Residing in Health Care Institutions in Canada" (Ottawa: Statistics Canada, 1991), https://publications.gc.ca/collections/collection_2018/statcan/CS82-615-6-eng.pdf
- 7 Elisabeth Cloutier, Chantal Grondin, and Amélie Lévesque, "Canadian Survey on Disability, 2017: Concepts and Methods Guide" (Statistics Canada, 2018), ISBN 978-0-660-27535-2, <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018001-eng.htm>
- 8 Statistics Canada, "2020 Nursing and Residential Care Facility Survey", https://www.statcan.gc.ca/eng/statistical-programs/instrument/5342_Q1_V1
- 9 Canadian Institution for Health Information, "Canada's seniors population outlook: Uncharted territory" (2017) <https://www.cihi.ca/en/infographic-canadas-seniors-population-outlook-uncharted-territory>
- 10 Ashley Kieran Cliff et al., "COVID-19 Mortality Risk in down Syndrome: Results from a Cohort Study of 8 Million Adults," *Annals of Internal Medicine* 174, no. 4 (April 2021): 572–76, <https://doi.org/10.7326/M20-4986>
- 11 Public Health England, "Deaths of People Identified as Having Learning Disabilities with COVID-19 in England in the Spring of 2020," (2020), https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_-_learning_disabilities_mortality_report.pdf