

# Including People in Institutions in Federal Disability Data

This is a plain language document of a research paper. The research paper is called **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.

## SUMMARY

This paper is about people with disabilities who live in institutional settings. It is about how they are not included in surveys and other information collected about people with disabilities.

## THE ISSUE

The last survey of people with disabilities who live in institutions was done in 1991. The surveys used today do not include this group. This means there are serious gaps in the information collected in the surveys. It also means it is hard to make disability policy, or guidelines, that include this group. Without this information, it is hard to see if Canada is meeting human rights commitments for people with disabilities. This information will be critical as new policies and programs develop. This includes the Canadian Disability Benefit and the Disability Inclusion Action Plan.

## BACKGROUND - COLLECTING INFORMATION ABOUT PEOPLE WITH DISABILITIES

The United Nations named 1981 as the Year of Persons with Disabilities. This helped to create a committee that would look at the needs of people with disabilities. This committee made a report. The report had many recommendations. These were meant to help include people with disabilities. One was about information, also called 'data.' It stated that countries need to collect more information about people with disabilities.

In 1986, the first survey on disability in Canada was done. Statistics Canada did the survey. Their goal was to make a national database of people with disabilities. This included people who lived in institutions. The voices of people with disabilities were very important in this survey. People with disabilities in institutions were interviewed in person.

This survey was done again in 1991. It showed that more than 247,000 people with disabilities were living in health care institutions. It also showed that more women and girls with disabilities lived in institutions. This survey got good information from people in many different sizes of institutions. This survey was stopped in 1991.

---

A new survey was started in 2001. It was changed and renamed in 2012. It is called the Canadian Survey on Disability. In 2017, the way information is collected for the survey was changed. Now, this survey does not collect information from people living in institutions. This means there are gaps in the information about living with a disability in Canada. This also means that policies, or guidelines, are made without considering the needs of this group. People with disabilities living in institutions must be included in national surveys about disability.

## **KEY POINTS TO CONSIDER**

Right now there is only one national survey on institutions. That survey does not collect information directly from people with disabilities. Instead, the information is collected from people who work at the institution. The last national survey that spoke directly to people with disabilities in institutions was done over 30 years ago.

There have been many changes in big institutions in the past 30 years. Many provinces have closed large institutions. But long term care systems have grown and expanded. This is because of Canada's growing senior population who need care. These changes show that there are many Canadian's who are not included in national data because they are in institutions.

The Covid pandemic showed how important this information is. There were more than 18,000 deaths in institutional settings. This information is especially important for people with intellectual or developmental disabilities. They are more than twice as likely to die from Covid than people of the same age without disabilities. It is hard to make sure more vulnerable people get vaccines first without this information from institutions. It is necessary to have data on this group in order to plan for emergencies or situations like the pandemic.

New programs and guidelines cannot meet the needs of all Canadians with disabilities without knowing what these needs are. When people with disabilities who live in institutions are left out of collecting data, they will not be included when new programs and guidelines are developed.

## **RECOMMENDATIONS FOR CHANGE**

There is a best practice that includes people with disabilities who live in institutions in data collection. It is done by directly engaging people who live in these spaces. This is in keeping with the disability community's motto of 'Nothing about us without us.'

This is different than how data is usually collected. But engaging directly with people can allow for more data to be collected about people's finances or health or basic needs.

The earlier surveys collected this information. The surveys we use today can and should do the same thing. It would give a better understanding of disabled life in Canada. It would help when making guidelines or policies. Statistics Canada should work with other departments to do this kind of survey. This includes Employment and Social Development Canada. It also includes working with the Disability Inclusion Action Plan group.