

Institutionalization and Long-Term Care Facilities

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

SUMMARY

This paper is about where people with intellectual or developmental disabilities live in Canada. It is about places called 'long term care facilities.' This information is about the situation in Canada.

THE ISSUE

People labelled with intellectual or developmental disabilities are being institutionalized. This happens when they are placed in long term care spaces. These spaces are very institutionalized settings. People do not have any choice in how they spend their time. They do not have any choice around when or what they eat. They do not have any choice in who provides their care. They do not have any choice about who they live with. Long term care spaces go against the right to access community living and choice. The federal government is responsible for increasing affordable housing, home care services and disability benefits. The right to live in the community is protected by Article 19 of the Convention on the Rights of Persons with Disabilities. The right to live in the community is necessary for the health, wellbeing and freedom of labelled people.

BACKGROUND –WHAT IS A LONG TERM CARE FACILITY?

A long term care facility is an institution where people live. These places are meant to house people who have complex needs. They are meant for people who need 24 hour support.

Long term care is mostly used for people with disabilities who need care rather than older people who need care. Over the last 60 years, long term care has been used for people with intellectual or developmental disabilities that need more support. In Ontario, there are more than 3,200 labelled people in these spaces. This means that they have to live in an institution rather than in the community. These places are often a last resort for labelled people. They end up in these places when there are no spaces in developmental services.

People with intellectual or developmental disabilities end up in long term care because of gaps in these three areas.

- Community living service
- Affordable housing
- Home care

Long term care is overseen by the provinces. But it is delivered through private and public companies. This means the services are not the same in each place. Over the past ten years, there has been an increase in funding for long term care facilities. But there has been very little increase in funding for community living services.

KEY POINTS TO CONSIDER

Access to housing

Research shows that 91% of Canadians plan to support themselves to live in their own homes as long as possible. And almost 100% of seniors (65 years and older) want to support themselves to live in their own homes too.

Long term care is an 'institutional environment.' This means that people who live here do not have the freedom of choice or the right to make their own decisions about day-to-day things. These are some of the things that make it an institution.

- Meal times are scheduled and menus are fixed
- Bathing is scheduled
- Furniture is all the same
- Recreation is limited
- Personal privacy is lacking

Long term care does not support the rights of people with disabilities to make their own choices and decisions. These rights need to be supported. The government of Canada and the provinces have signed and agreed to follow the Convention. This means they need to protect the "right for all people with disabilities to live in community with choices equal to others."

Right now, labelled people do not have adequate choices in where they live or who they live with. Affordable housing is a key part of community living for people with intellectual or developmental disabilities. But there are growing waitlists for affordable housing and residential services all across the country. Waitlists show that there is a lack of choice in housing. Waitlists mean that people are more likely to take the first place available. They may not want to risk losing their place on the list.

At the same time, there is not much increase in community living services for labelled people. The result is that more than 100,000 do not have access to the affordable housing that they need.

This shows the gap in available services for labelled people with more complex healthcare needs. They are in long term care because of the lack of services to support them to live in the community.

Access to home care services

It is not just lack of access to housing that increases the use of places like long term care. The lack of access to home care services also means that more people end up in these spaces. Research from 2016 showed that at least 433,330 Canadians had unmet home care needs. Unmet needs were caused by not having enough hours of home care and the lack of available services.

Home care services are the responsibility of provinces, territories and cities and towns. This means services are not the same in all places across the country.

Covid and long term care

During the Covid pandemic, 81% of all Covid deaths in Canada happened in long term care.

People in long term care died from Covid. But they also died because of staffing shortages and a lack of care. They died from neglect from lack of food and water. They were also very isolated.

Covid rules for long term care meant that people with disabilities could not see their family, friends or other caregivers. Covid rules did not allow any visitors in long term care. This made these places even more institutional. Visitors are important for the health and safety of some residents in long term care. Besides not having visitors, people were even more isolated because they didn't have access to the internet.

CONCLUSION

Long term care spaces are not made for people with intellectual or developmental disabilities. These places do not provide any of the following supports or services.

- Recreation, activities or things to do
- Health and social supports for labelled people
- Employment opportunities
- Education opportunities
- Volunteer opportunities

In Ontario, a guideline was developed to respond to this use of long term care. But the guidelines do not work to make these settings any less institutional.

RECOMMENDATIONS FOR CHANGE

People with intellectual or developmental disabilities are living in long term care spaces when they could be living in the community. Changes need to be made to remove these barriers to community living. There needs to be funding and energy put towards this issue. Here are three recommendations for change.

1. There needs to be better access to housing for labelled people. Housing benefits must work for people with disabilities. These benefits must reflect the unique needs and increased costs of living with a disability. There needs to be more housing on reserves for First Nations adults with disabilities.
2. There needs to be better access to home care services. This will increase the ability of people with complex disabilities to live in the community. Right now, five times more money is being spent on long-term care than on home care. If even half the amount of money spent on long-term was used for home care then more people could live in the community.
3. There needs to be more effort put into ending the lifelong poverty of labelled people. This can be done through a Canada Disability Benefit. Poverty and lack of affordable housing means that more people with disabilities will end up in institutions. Any Disability Benefit must include people who live in long term care and get a provincial allowance.