

I N S T I T U T I O N WATCH

BY THE CANADIAN ASSOCIATION FOR COMMUNITY LIVING

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Monitoring the progress toward a vision of full community living for all persons with intellectual disabilities.

This is a newsletter by the People First of Canada-CACL Joint Task Force on Deinstitutionalization. For more information, contact Don Gallant at (416) 661-9611.



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BY DON GALLANT

The Canadian Association for Community Living (CACL), in conjunction with the People First of Canada - CACL Joint Task Force on Deinstitutionalization, presents its introductory edition of *Institution Watch* - a quarterly newsletter documenting the status of deinstitutionalization across Canada. As this is the first edition, most of the commentary is from the Task Force. In future editions, we would like to highlight stories from individuals and families across the country who have lived in, are still living in, or have fears of being admitted to an institution.

We hope this newsletter can act as a catalyst to remind us that many individuals still reside in institutional environments. Unless we remain vigilant, many more will be admitted to such facilities in the future. We encourage you to submit your stories and/or perspectives on this issue. E-mail them directly to Don Gallant (dgalant@roadrunner.nf.net) for inclusion in our next edition.

"INSTITUTIONS DENY YOU A LIFE - THEY TAKE AWAY YOUR ABILITY TO KNOW AND CONNECT TO YOUR FAMILY - YOUR COMMUNITY - DENY YOU THE OPPORTUNITY FOR FRIENDSHIPS. INSTITUTIONS TAKE AWAY THE ABILITY TO HAVE RESPONSIBILITY FOR YOUR OWN ACTIONS. AN INSTITUTION IS A PLACE WHERE PEOPLE ARE NOT PERMITTED TO DREAM."

- Pat Worth

MESSAGE FROM THE TASK FORCE

We all know that institutions are not new. They have been around for hundreds of years. At one point, our society thought they were the best places for people with intellectual disabilities to live. Families were told that services could be best and more cheaply delivered in large settings; that institutions were the safest places for their sons and daughters; and that people with intellectual disabilities did not have the skills to live in the community. **We now know that this is false!**

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We now know that when asked, people choose not to live in institutions. We know that institutions deny people basic rights of citizenship, personal control, decision-making and independence. We know of the abuse, isolation and personal suffering that often occurs in these places, based on stories told by people who have lived in these institutions. We also know that institutions are not defined just by size.

TASK FORCE MEMBERS

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DID YOU KNOW? Many of us assume that institutionalization no longer occurs in Canada and that people with intellectual disabilities now live in their communities with families, friends and neighbours. After all, in a country so rightfully proud of its diversity and tolerance, it makes sense that all Canadians should have the right to choose where they live. Doesn't it? Unfortunately, in 2003:

- Over 20,000 Canadian citizens with disabilities are living in health-related institutions such as seniors' facilities, nursing homes, acute care hospitals, long-term care facilities and personal care homes, as opposed to ordinary homes in the community.
- More than 12,000 persons remain trapped in institutional facilities designed specifically to house persons with intellectual disabilities.

WHAT IS AN INSTITUTION?

ANY PLACE IN WHICH PEOPLE WHO HAVE BEEN LABELLED AS HAVING AN INTELLECTUAL DISABILITY ARE ISOLATED, SEGREGATED AND/OR CONGREGATED. AN INSTITUTION IS ANY PLACE IN WHICH PEOPLE DO NOT HAVE OR ARE NOT ALLOWED TO EXERCISE CONTROL OVER THEIR LIVES AND THEIR DAY-TO-DAY DECISIONS. AN INSTITUTION IS NOT DEFINED MERELY BY ITS SIZE.

- Many provinces and territories are beginning to move away from earlier commitments made to complete institutional closures, while others have yet to indicate plans to close facilities.
- In at least two areas, new institutions are being built that will house persons with intellectual disabilities.
- Current government policy in many provinces and territories restrict access to required funding and to the disability supports and community services necessary for community living.
- More and more, individuals with intellectual disabilities and their families are presented with options that do not support lifestyles of choice, but rather support entry into group home programs and/or other places where people are congregated.
- In many provinces and territories, persons with intellectual disabilities are being admitted on a routine basis to institutions, directly violating a stated policy of deinstitutionalization.

WHAT DO WE MEAN BY DEINSTITUTIONALIZATION?

Renewed efforts to assist persons to leave institutions must be guided by values and principles that are known to achieve positive outcomes. Deinstitutionalization must be about more than simply closing large institutions, about more than simply replacing large institutions with smaller ones, about more than creating networks of group homes, and ultimately about more than substituting isolation outside the community for isolation within the community.

TIME AND TIME AGAIN, WE HAVE SHOWN THAT WITH APPROPRIATE SUPPORTS, ALL PERSONS, REGARDLESS OF TYPE OR EXTENT OF DISABILITY, CAN LIVE IN AND CONTRIBUTE TO THE COMMUNITY.

- Excerpt from letter to
Premiers
sent by Task Force,
June 2003

A deinstitutionalization plan must ensure that people have:

- The right to choose where they will live, and with whom;
 - Services/programs that are directed and controlled by the person and that are respectful of his or her right to make choices, and take risks;
 - The right to individualized living arrangements and control over the required individualized funding;
 - The necessary disability-related supports needed to fully participate in the community;
- Support, as necessary, from friends/family/advocates to assist in decision-making (supported decision-making);
 - Services that meet all of their needs and are of high quality, portable and accessible.

PEOPLE FIRST OF CANADA RIBBON CAMPAIGN

People First of Canada (PFC) has brought back its Ribbon Campaign to let Canadians know that too many people are still locked in institutions; to express their horror that Canada continues to keep institutions open; and to show that they are angry that new kinds of institutions are being built. The ribbons are black and yellow- the black honours the many people who have died in institutions and the yellow represents liberation. The ribbons are available from People First of Canada (204-784-7362) or from any of the People First groups across the country. Please show your support, buy a pin, and wear it with pride! For more information on PFC, visit their web site at: <http://www.peoplefirstofcanada.ca/>.



PFC would like you to participate in their Ribbon Campaign 2004

PROVINCIAL AND TERRITORIAL STATUS

A LOOK AT WHAT'S HAPPENING ACROSS CANADA

Newfoundland and Labrador closed both its institutions around 1992. They also assisted people to leave the provincial psychiatric hospital. However, many people still live in large settings such as personal care homes, nursing homes and seniors' facilities.

Nova Scotia has 685 people living in regional residential centres and adult residential centres.

There are also 18 residential care facilities, which have 15 or more beds. Many of the people living in the residential care facilities are mental health consumers or people who have been forgotten for a variety of reasons.

In *Prince Edward Island* there are still three institutions which house about 100 people in total. P.E.I. has no plans to close these facilities in the near future.



In *New Brunswick* deinstitutionalization efforts in the 1980s led to a dramatic downsizing of the province's largest institution. Centracare is now a 50 bed psychiatric facility (it once housed 1,600 people, including many people with intellectual disabilities). The province's institution for children was also closed in 1985. Institutionalization for many people still occurs through the placement of people in nursing home facilities and in special care homes. Since the late 1990s, however, the Government of New Brunswick has

increased funding for in-home supports and has also committed to a new disability framework that will develop individualized support options through a proposed Disability Support Program. A Disability Support Program pilot project is scheduled to begin in 2004.

In 1980 - 1981, nearly 5,000 people with intellectual disabilities lived in institutions in *Quebec*. By 1988, this number was down to 4,000. Today, this number is approximately 600. The Quebec government intends to close these institutions, but has not set a date.

In *Ontario*, there are three large institutions left with just over 1,000 people living in them. A few years ago, the government committed to closing the facilities by the year 2012. Progress went well for a number of years, but stalled in 2000. Since then, no one has left and a few people have been readmitted in recent months.

Manitoba closed Pelican Lake Training Centre in 2000, a facility that housed 75 people with intellectual disabilities. Manitoba still has two institutions which have approximately 650 people living in them.

Shockingly, over 20,000 Canadian citizens are still living in institutions across the country in 2004.

"I DARE THEM TO GO AND LIVE THERE LIKE WE DID FOR TWO DAYS AND THEN MAYBE, JUST MAYBE, THEY'D KNOW WHY WE WANT IT CLOSED SO NOBODY HAS TO LIVE THERE."

- Bill Hogarth,
former resident of
Valley View Centre in
Moose Jaw
(Bill lived there for 42
years)*

Although there are no definite plans for closure, 10 to 15 people per year do leave for community options and 10 to 15 people die each year. There are very few admissions to this facility. Recently People First of Manitoba met with the new Minister of Family Services and urged the government to plan for further closures and support the establishment of a federal Community Transition Fund.

In *Saskatchewan*, there are approximately 350 adults living in institutions. The Valley View Centre in Moose Jaw is the only institution in the province. On average there are five-ten new admissions each year.

Currently in *Alberta*, there is a review of the future of Alberta's largest remaining institution. The first report on possible future options will be out shortly. Alberta Association for Community Living (AACL) will actively participate in the decision-making process that will follow the release of the report. The results of this review will probably affect the future of all remaining smaller institutions, of which there are about four. There is no active process of deinstitutionalization currently in place in Alberta, however, the number of individuals who are institutionalized continues to decline annually through death and though the few who leave. AACL, in cooperation with the Persons with Developmental Disabilities Provincial and Community Boards, is leading the development of new provincial resources to support individuals with complex behavioural needs who are at times threatened by institutionalization.

British Columbia has closed all its large institutions. There is one program left that houses 25 people and it is slotted to close in 2004. There are a number of homes with 8 to 12 people living in them. There are many people living in group home settings, which are not as individualized as people would like.

Yukon has no traditional large institutions. There is an extended care facility which houses six to ten people with intellectual disabilities.

The Northwest Territories have no institutions. Currently, there are approximately 10 people from NWT being housed in institutions in other provinces.

Nunavut has no institutions. Similar to NWT, some people with intellectual disabilities are living in institutions in other provinces. Some people who have returned to Nunavut from institutions are now living in group homes.

**MARCH TO QUEEN'S PARK
ON APRIL 5, 2004,
STUDENTS FROM LOYALIST
COLLEGE INVITE YOU TO
JOIN THEM IN A MARCH TO
QUEEN'S PARK TO URGE
THE GOVERNMENT TO
SPEED UP THE CLOSURE OF
INSTITUTIONS. FOR MORE
INFORMATION, CONTACT
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**PROVINCIAL
AND
TERRITORIAL
POLICY
REGARDING
DEINSTITUTION-
ALIZATION**

**HOW ARE
GOVERNMENTS
RESPONDING TO
OUR CONCERNS?**

During the summer of 2003, the People First - CACL Joint Task Force wrote letters to every Premier in Canada to remind them that there are still hundreds of vulnerable people being inappropriately housed in institutions, and to pose some basic questions.

1) What is your government's position and/or policy with respect to deinstitutionalization.

2) Do persons with intellectual disabilities in your province still reside in institutional environments? And if so, what specific plans does your province have to address this matter.

3) Would you be willing to engage in multilateral discussions with your provincial/territorial counterparts, the federal government and community organizations toward the development of a national framework for deinstitutionalization.

To date we have received responses from every province except for Yukon, Nunavut, Northwest Territories, or Prince Edward Island. Many of the responses have been positive and indicate a continued support for deinstitutionalization efforts. For example:

"We would be willing to engage in multilateral discussions with Provincial/Territorial counterparts, the federal government and community organizations regarding the deinstitutionalization process and would be more than willing to share our learnings on this subject."

- Gerald Smith

**Former Minister of Health and Community Services
Newfoundland and Labrador**

"We recognize that our province's current model of service requires a review and changes in an effort to better address and meet the needs of persons with disabilities in our province. To this end, the Department of Community Services has initiated the Community Supports for Adults Renewal Initiative. The results of this will be a new model of service delivery based on input from consumers, stakeholders...and best research practice. The goal will be to have a model which ensures coordinated, integrated and flexible services. We support the work of People First of Canada and CACL and would be pleased to engage in any discussions related to the development of a framework on deinstitutionalization."

- David M. Morse

**Minister of Community Services
Nova Scotia**

“I can assure you that our government strongly believes in deinstitutionalization and will continue, within available resources, to strive to develop community based supports that can meet the needs and desires of individuals with disabilities. We also believe that deinstitutionalization is a process which requires careful planning to ensure that resources are readily available in the community. I would be interested in learning of about the response from other jurisdictions and any plans that might be brought forward to discuss this important issue.”

- Drew Caldwell
Former Minister of Family Services and Housing
Manitoba

“The Ontario government is committed to providing supports for people with development disabilities so that they can participate in community life and live as independently as possible....The Ministry has a long standing goal of reducing the number of individuals living in large institutions. Since 1974 the Ontario government has worked closely with community agencies, advocacy groups and people with developmental disabilities and their families to move away from segregated institutional living toward a more integrated approach in the community. In 1987 the Ontario government made a commitment to close ministry operated facilities (institutions) within 25 years. Three ministry operated facilities remain open for people with developmental disabilities and our government is committed to their closure.”

- Brenda Elliott
Former Minister of Community, Family and Children’s Services
Ontario

“Saskatchewan has been and continues to promote community based services for people with disabilities. In this context the government of Saskatchewan would be interested in participating in discussions with our provincial, territorial and federal counterparts regarding any new deinstitutionalization initiatives.”

- Glenn Hagel
Former Minister of Community Resources and Employment
Saskatchewan

“Our goal is to raise the quality of life for every person in this province. We are doing our best to make sure that we create an opportunity in the future for all British Columbians to build on. We are also focused on being responsible with taxpayers’ dollars and are determined to get maximum value for each one of those dollars.”

- Gordon Campbell
Premier of British Columbia

NEXT STEPS FOR TASK FORCE

To date, the Task Force has written follow-up letters to all Premiers requesting a meeting with provincial or territorial officials to discuss next steps in Canada's deinstitutionalization efforts.

We will publish any responses in the next edition of this newsletter. The Task Force has also reached an agreement with CBC Radio to air a national commentary on the continued institutionalization of persons with intellectual disabilities in this country. Tentatively entitled "A Promise Broken," it will feature interviews with individuals and families and will provide a critical analysis on why institutions continue to exist in this country. Finally, the Task Force will continue pressing for the creation of a Community Transition Fund in the upcoming federal budget and continue to call for a national plan for deinstitutionalization.

TELL US WHAT YOU THINK

In order to create a national plan for deinstitutionalization, we need to partner with all levels of government, advocacy organizations, families, friends and, most importantly, with persons who are currently residing in institutions. Indeed, all of us need to work together to help spread the message that *the institutionalization of persons with disabilities is wrong*. Institutionalization represents the most basic form of exclusion and denial of citizenship, and stands in sharp contrast to Canada's vision of "equality, inclusion and independence."

The Task Force would love to hear your opinions, insights, stories and experiences on deinstitutionalization efforts throughout the country. We also request that you help us keep watch by alerting us of any new developments in your communities. Together, we can guide our governments to commit to a total rejection of institutions, and build a country that recognizes the value and inherent worth of all Canadians. Contact Don Gallant by e-mail at dgallant@roadrunner.nf.net or phone the Canadian Association for Community Living (416-661-9611).

CACL gratefully acknowledges the Government of Canada (Department of Social Development) for supporting our national Community Inclusion Initiative.

*as quoted in Planet S and Prairie Dog newspapers

