

INSTITUTION WATCH

BY THE CANADIAN ASSOCIATION FOR COMMUNITY LIVING

SUMMER 2004
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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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MESSAGE FROM THE TASK FORCE

Unfortunately, institutions still play a role in the lives of persons with intellectual disabilities. Thousands of our fellow citizens remain trapped in institutions — our vision of a country where *all* persons with intellectual disabilities live in the community, as stated in our Community Living 2000 document, remains unfulfilled! This newsletter serves to remind us of this unacceptable reality, its stories and comments renew our efforts toward institutional closures. Please share this newsletter widely — with colleagues, family, friends, government officials and politicians — so that they too may assist in our efforts.

The response to our first newsletter was very positive, and we thank you for all your positive comments and feedback. We received many submissions for inclusion in this edition. For this we also thank you. Unfortunately, submissions exceeded our available space, and we were unable to print all of them. These will be featured in our next edition.

“AN INSTITUTION IS ANY PLACE IN WHICH PEOPLE WHO HAVE BEEN LABELED 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.”

Deinstitutionalization Task Force

ONTARIO - INSTITUTIONAL CLOSURES ANNOUNCED

**Excerpt from press
release by the Ontario
Ministry of Community
and Social Services,
September 09, 2004**

\$110 Million To Strengthen Community Services And Close Institutions

TORONTO – The Ontario government is strengthening supports for Ontarians with developmental disabilities by investing in community services and launching a major

review of the province's developmental services system to make sure it is fair, accessible and sustainable, Minister of Community and Social Services Sandra Pupatello announced today.

In 1987, the Ontario government committed to closing the province's remaining facilities within 25 years — a commitment that has been supported by successive governments since then. The phasing out of the remaining institutions completes Ontario's evolution from an institution-based to a community-based system that promotes greater inclusion, independence and choice.

"Those who used to live in institutions are now living in neighbourhoods throughout Ontario," said Dr. Ivan Brown, Director of the Disability Support Unit at the University of Toronto. "The era of institutions has passed, and we need to help those still living in institutions move to neighbourhoods of their choice as soon as possible. I'm pleased to see the provincial government moving in this direction."

"We have come a long way in understanding the needs of people with a developmental disability," said Pupatello. "We still have a long way to go, but today, we start building the foundation for the future — a foundation that will help us build strong, inclusive communities that provide all Ontarians with a quality of life second to none."

TASK FORCE MEMBERS

Pat Worth
Cathy O'Donnell
Marcella Baldwin
Paulette Berthiaume
Peter Bourne
Cheryl Gulliver
Norm McLeod
Peter Park
Gordon Fletcher
Heather Tracey
Richard Ruston
Shane Haddad
Shelley Rattai
Pat Golding
Mary Rothman
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COMMUNITY LIVING ONTARIO RESPONDS TO INSTITUTION CLOSURES

Excerpts from press release by Community Living Ontario, September 09, 2004

Commitment to close institutions lauded

The 10,000 individuals and families who are members of Community Living Ontario are thrilled that the more than 1,000 people who currently reside in Ontario's three developmental services institutions will soon have the opportunity to live as citizens in the community.

"There is no question that all people can and should have the opportunity to live in the community," says Keith Powell, executive director of Community Living Ontario. "For those in these institutions, this announcement gives them the first opportunity they've ever had to choose where in the community they will live. That, itself, is cause for celebration."

Donald Parent, of Wallaceburg, Ont., himself a person who once lived in all three facilities, is overjoyed with Minister Pupatello's announcement: "My friends, those I left behind, will now be out and able to experience freedom and all that the outside world has to offer."

CLOSING THE REMAINING INSTITUTIONS IS THE RIGHT THING TO DO — ON BOTH HUMANITARIAN AND FISCAL GROUNDS.

Closing institutions has been the commitment of all governments in Ontario, regardless of political stripe, since 1987. “We are pleased that the current government has chosen to honour this commitment to those who will now have the chance to experience community life. We thank the Minister for her determination to move forward with this.”

The Community Living movement has been a leader in supporting those who move out of institutions and in helping local communities strengthen their capacity to welcome people. Over the years, thousands of people have already left institutions and returned successfully to their communities.

“We have more than 50 years’ experience in helping to make inclusion in the community a reality,” says Mr. Powell, “We are confident that, with adequate planning and support, we can build upon those previous successes so that the transition for these 1,000 people will be equally successful.”

ON THE RECENT ELECTION

Liberal Response on Deinstitutionalization

The following excerpt was received from The President of the Liberal Party of Canada, Mr. Ken Eizenga, on behalf of the Liberal Party and Paul Martin in reply to questions which were sent to all parties by the Saskatchewan Association for Community Living.

“The Liberal Party of Canada recognizes and understands persons with disabilities and their families’ concerns related to housing, home care and support for caregivers. The emphasis should be on providing the greatest opportunity possible for people with disabilities to retain their independence and continue to live in their own homes. Of course, this means dealing with a complex web of issues, including income support, housing, and home-care.

A Liberal government will work together with the provinces and territories to bring more choice for people with disabilities in their living arrangements. We will increase funding for the Residential Rehabilitation Assistance Program through the Canada Mortgage and Housing Corporation, which, in combination with the Home Adaptation for Seniors Independence

“DURING THE RECENT FEDERAL ELECTION THE ONLY THING THAT REALLY STUCK OUT WITH ME IS THE GENERAL LACK OF AWARENESS OF THE EXISTENCE OF THE INSTITUTIONS. I REALLY BELIEVE A LOT OF THE CANDIDATES HEAR “INSTITUTION” AND AUTOMATICALLY THINK OF PSYCHIATRIC HOSPITALS, AND THAT’S WHY THEY THINK IT’S A HEALTH ISSUE. I THINK THERE NEEDS TO BE A REAL PUSH TO EDUCATE ABOUT AND EXPOSE THE INSTITUTIONS FIRST AND ONCE PEOPLE KNOW ABOUT THEM, THEN SAY OK, CAN WE NOW WORK TO CLOSE THEM!”

Laurie Larson, Saskatchewan

program, helps ensure people with disabilities and seniors can live independently in their own home or in an adapted residence.

In addition to this, a Liberal government will introduce a Home Care Program to provide an agreed-upon, minimum basket of services across Canada. A newly created Home Care Fund, totaling \$2 billion over five years, will be used to fund the program. The money will be allocated on a per capita basis to provinces and territories that commit to provide an agreed-upon, minimum basket of home care services."



PRINCE EDWARD ISLAND

PEI People First recently launched our new booklet called "On the Road to Freedom" on May 29th at our conference in Charlottetown. About 65 People First members came to the conference. The

book is about people who used to live in an institution but who moved out. In my introduction to the book, I say that "when I read these stories it seems like it takes a long time to leave the institution behind. Yes, they are out of the institution but they still don't have the support they need to be happy in the community".

Pat Worth, who with Cathy O'Donnell chairs the CACL/PFC Task Force on De-institutionalization, was our guest speaker. He talked about the idea that an institution is more than the four walls around you — it can be a way of thinking. Pat talked about the work he does on the Task Force.

"I DON'T HAVE THE WORDS TO SPEAK IT OUT BUT IF I HAD THEM I WOULD TELL YOU. IN THERE IS NOT THE RIGHT PLACE. IF I WENT BACK IN I'D BE IN FOR LIFE. THERE ARE A LOT OF PEOPLE WHO ARE IN THERE FOR LIFE. I'M BETTER OUT".

Quote from "On the Road to Freedom"

After Pat spoke, I asked our members to write a petition to the government. We are asking the government to close down the institutions and get people better homes in communities. We want people to have respect, to have people to listen to them and not make fun of them or put them down. We'll have a better community if we help each other out and respect each other.

We have talked to Chester Gillan, the Minister of Health and Social Services, about institutions — he was interested, and to Robert Ghiz, the Leader of the Opposition — I would like to talk to the Premier soon and hopefully we can work together with them as a team to make a better community for everybody.

Submitted by: Dan Keaveny, President of P.E.I. People First

QUEBEC

Decision-makers are too lax regarding the deinstitutionalization of Rivière des Prairies

At its Annual General meeting on May 27, 2004, QACL together with its member associations, decided to contact the Minister of Health and Social Services of Quebec, M.P.P. Philippe Couillard. To expose the fact that a hundred people with intellectual disabilities who should have left the institution are still at Rivières des Prairies and that the necessary services are provided by the staff of a rehabilitation center. This situation was caused by the insistence of parents of children who had been in the institution for decades and who are opposed to their inclusion in the community.

In her letter to the Minister, Lucie Cholette, President of QACL, pointed out that the Minister infringes the policy of his Ministry and stressed the negative impact of such a decision that opens the door to reinstitutionalization.

Submitted by: Diane Milliard, Executive director, CACL

ALBERTA

As reported in the last edition, there is a review underway with respect to the future of Michener Centre, Alberta's largest remaining institution. This review was conducted under the auspices of the regional Persons with Developmental Disabilities (PDD) board responsible for the operation of this institution. As part of the review process the board hired a health based consulting firm to generate possible future options for the institution. AACL's executive met with the consultants to share our view on the future of Michener Centre, however the consultants seemed more interested in defending the continuation of the facilities in contrast to hearing the voices of families and individuals who shared a view of a future without an institution, instead living an inclusive life in the community.

The consultants report, as have many in the past, exposed the shortcomings of the institution, in particular how the lives of many of the individuals confined to the facility remained unfulfilled. Other aspects of the report suggest the individuals housed there have less significant disabilities than that claimed by the institution and as well, that the institution did not fairly capture the voices of individuals who wanted to leave. The report identified eight possible options for the future, almost all of which would see some continuation of the facilities, although possibly with less people living on the grounds.

ON ANOTHER NOTE AACL HAS BEEN ASKED TO ASSIST A CHILDREN'S REGIONAL AUTHORITY IN ENDING THE INSTITUTIONALIZATION OF TWO CHILDREN WHO REMAIN IN A VERY SMALL FACILITY FOR ADULTS. PART OF THIS WORK WILL INCLUDE THE IMPROVEMENT OF REGIONAL COMMUNITY SUPPORTS TO FAMILIES WHO HAVE CHILDREN WITH COMPLEX HEALTH CARE NEEDS.

The PDD board, in turn, has developed its own proposal for the future of the institution and largely ignored the report of its own consultants. The board has recommended and sought approval to essentially rebuild the facility in a more modern guise resulting in the continuing institutionalization of the vast majority of individuals who currently reside there, while creating the possibility for institutionalization of others in the future. The board's position is based on their perception that almost all of the individuals living there now and their families want to remain living on the grounds of the facility. The board's request to proceed to re-develop the facilities, without any specific plan or costs, has gone to the Provincial PDD Board for approval. The Provincial Board is now reviewing this request. However, in all likelihood whatever decision will be made, it will be a political one.

AACL will be meeting with as many of the provincial board members as possible to outline our opposition the rebuilding of the facilities and the continuing institutionalization of individuals with developmental disabilities. In addition AACL will be producing a critical analysis of the consultants' report and the PDD board's proposal. Other strategies will include a province wide political advocacy initiative and a legal review of the Persons with Developmental Disabilities Community Governance Act. The purpose of this Act is to further the inclusion of people with developmental disabilities. We will continue to advocate for people in Michener Centre to be supported to live in the community.

Submitted by: Bruce Uditsky, Executive Director of the AACL

TRAPPED

**Submitted by
Pat Worth**

A couple of months ago an event happened in my home that brought me back to my history as a vulnerable child and as a young man. On April 13 while I was lying in bed, not feeling very well, I smelled something. I got up out of bed to check what was going on, I became very alarmed when I saw smoke coming into my apartment from under the door way. I opened the door and saw nothing but smoke everywhere, I heard voices on the stairway but I couldn't see the stairway. I closed the door and a couple of seconds later, the fire alarm finally went off. As I went out into the balcony, I finally realized, I'm trapped. The fire was directly below me on the third floor. As I heard the firemen telling us to stay on our balconies, I looked over at all of the faces of people on their balconies and I saw the look of fear of being so vulnerable.

**MALLORY'S FUTURE LIES IN HER
COMMUNITY WHERE SHE WILL
CONTINUE TO SPREAD HER WINGS,
FIND HER RIGHTFUL PLACE,
CONTRIBUTE, PARTICIPATE AND
BELONG. AS HER FAMILY WE WILL
SETTLE FOR NOTHING LESS.**

Barb Horner, Nova Scotia

We were trapped and we were depending on champions to get us out. People with physical handicaps were especially vulnerable because some would not be able to get out and others would need assistance. In the face of real danger, it takes a champion to save people. As I was standing out on my balcony, I looked over at my

neighbours and no matter what they were doing they all had the same face — the fear of being trapped.

With the fear of fire and smoke getting closer to us, the cold freezing rain and wind blowing right at us, I can tell that we were all wondering the same thing 'are we going to be rescued?'. This was taking a long time and putting the fire out and gaining control of the smoke seemed like a difficult task. I saw the firemen taking people out on stretchers. I knew they were badly hurt. My fellow neighbours were getting hurt. By the time they came for us on the 4th floor, I was more than ready to leave. I had to wait longer because the fire was directly under me.

Finally everything was under control. Later, I learned that a 75 year old woman died in that fire and it was caused by smoking. There wasn't a champion there for all of us that day. Some people were evacuated and had to stay in hotels, other people such as myself stayed with friends until it was okay to return. The system did not work, we were not safe in our homes. When I look at the faces of the same people who were trapped that day, I don't see the same fear, I see people going on with their lives. It all brought me back to how vulnerable I felt as a child and a young adult being locked up in a system, feeling trapped and with no way to get out. I promised myself that I would never be that vulnerable again but it made me realize that we can all become very vulnerable in a matter of seconds when systems don't work or congregate our lives.

There are still many citizens who are trapped in one institutional system or another across the world today because of the way people think. An institution is not just a place; it is the way people think. The people who were trapped that day will not think about the fact that many people are trapped in institutional systems where they have no freedom at all, no human rights and the sense of powerless surrounds their lives at every moment, for these people the sense of being trapped is every second of their lives, that is an institutional life. I light the candle of hope and compassion for a 75 year old woman who didn't have a champion that day and also for all people who need champions and that includes all of us. We all need to be rescued sometimes because we all have many different fires in our lives and sometimes it's not that easy to put them out by ourselves. We need to feel powerful so we all need help with putting out fires that make us feel very vulnerable. When systems don't work, we need champions. Think about it — I think it's worth thinking about!

Submitted by: Patrick Worth

MANITOBA

ACL-MB has recently begun collecting stories of life after leaving Pelican Lake Training Centre, an institution that closed four years ago in Manitoba. We have created a questionnaire that examines issues such as control, autonomy, choice and decision making. We asked agencies to write a story about each person that they support and illustrate what has changed in the past three years. The final product will be released in the Fall of 2004.

BRITISH COLUMBIA

The legacy of Woodlands institution — Woodlands cemetery

Although BC saw the last of its large institutions for people with intellectual disabilities close in 1996, that doesn't mean today we are free of the effects of institutions. During the creation of the art project *From the Inside/OUT!* One thing that came to light — in addition to the stories of abuse — was that there had been a cemetery at Woodlands institution where over 3,300 residents were buried from the 1920s up until the 1950s. In 1976 the cemetery was officially closed when construction began nearby for an extended care facility. All except a very few grave markers were taken away. Many were recycled and used as paving stones. Some were even used to build a patio and barbeque firepit right on the Woodlands site.



Since 1999, BCACL and BC Self Advocacy Foundation (BCSAF) have been working to restore the cemetery. This has been a slow process, as the land where Woodlands once operated was slated to be sold and redeveloped, and there has been much controversy over how it should be used.

Nevertheless, BCACL and BCSAF secured an agreement from the provincial government to set apart the cemetery area, and a group of interested volunteers have continued to work with a landscape designer to plan the restoration. Part of our work was to salvage and create an inventory of as many cemetery grave markers as possible. There are now over 400 that will be returned to the cemetery in memorial walls. Some of our salvage work involved literally cleaning off mud and chipping away concrete from grave markers to reveal the names hidden underneath!

Since beginning this project, we have learned that what happened at the Woodlands cemetery is not uncommon for institutions that housed people with disabilities. Many state institutions in the United States have cemeteries that were desecrated, and there are several restoration projects underway.

The legacy of institutions reaches well beyond the time that they are in operation — and in BC, we are certainly seeing what this means. However, one of the unexpected positive outcomes of the recent work on BC institutions is that it has allowed many people to reconnect with friends they haven't seen since the institutions closed. Many have also become strong and outspoken advocates for righting the wrongs that happened in institutions.

Pat Feindel, Director of Communications, BCACL

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

Submissions: We encourage you to submit stories, Provincial/Territorial updates, pictures and or personal perspectives on this issue. Please mail them directly to Don Gallant at dgallant@nl.rogers.com for publication in our next edition (due out in December 2004).