

INSTITUTION 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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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! We hope this newsletter serves to remind us of this unacceptable reality, and that 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.

ONTARIO

MPP Sandra Pupatello (Lib-Windsor West), Minister of Community and Social Services for the Province of Ontario, was the guest speaker at the recent annual meeting of Community Living Windsor. Pupatello spoke with passion about her commitment to the vulnerable citizens of Ontario, and the services the province provides.

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

“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.”

Pupatello spoke of the status of the three remaining institutions in Ontario, which currently house 1,100 people with developmental disabilities. She referred to the promise made in 1977 to close these institutions. The provincial government's timeline of 25 years would take the final closure to 2012. Pupatello will make an official announcement about the future of the institutions in late August or the early fall.

She affirmed her dedication to the closure of the institutions. But she stated that it must be done with care, to ensure a better life for residents who will be repatriated to their communities, and a satisfactory transition for staff, some of whom have worked in the institutions for over twenty years.

TASK FORCE MEMBERS

Pat Worth
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ONTARIO UPDATE ON DEINSTITUTIONALIZATION

Ontario's long-standing plan to close all institutions that house people with intellectual disabilities has become stalled and it's time to get it back on track. In 1987, the Ministry of Community and Social Services said all 18 institutions, which housed more than 8,000 people, would eventually close. It was a humanitarian move to enable many to live in regular neighbourhoods, in apartments or houses, alone or with friends. Those requiring 24-hour care would live in community group homes. People could live closer to their families, participate in community activities, develop self-reliance and even gain employment. They would have more dignity and independence. The stigma and routine of an institutional life would be gone. Governments of all three parties supported the plan and today, 15 of the institutions have closed. The three remaining (with the number of residents in brackets) are: Southwestern Regional Centre (SRC) near Blenheim (285); Huronia Regional Centre in Orillia (353); and Rideau

Regional Centre in Smiths Falls (449). All are huge buildings housing a fraction of the people they once did. The savings on operating costs alone would probably be enough to support those people in the community. Then there's the real-estate value of the properties. SRC occupies a huge property along Lake Erie. Orillia's is on Lake Couchiching, and the Smiths Falls

institution, in eastern Ontario, is near the Rideau River — prime property worth millions of dollars. There's no shortage of needs that could be addressed with found money — or interest on it. Payments to the disabled from the Ontario Disability Support Plan (ODSP) have not gone up since 1993. The cost of living has gone up about 24 percent in the same period, prompting Community Living Ontario to suggest an eight percent increase in each of three years to catch up. As Premier Dalton McGuinty's Liberals prepare their budget, the

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

needs are so great and the resources so stretched, they need to look at all revenue sources. Closing the remaining institutions is the right thing to do — on both humanitarian and fiscal grounds.

The editorial, published by *The London Free Press*, appeared on page A8 on Monday, May 10th, 2004

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ON THE RECENT ELECTION

Liberal Response on Deinstitutionalization

The following excerpt was received from Mr. Ken Eizenga, President of the Liberal Party of Canada, 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 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.

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

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.

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.

"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"

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 and its member associations decided to contact the Minister of Health and Social Services of Quebec, 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 against the inclusion in the community of their children who have lived in the hospital for decades.

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.

ALBERTA

As reported previously, 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 and its facilities while living an inclusive life in community.

The 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. However, 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.

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 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.

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.

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 we 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 legal review of the Persons with Developmental Disabilities Community Governance Act which states the purpose of the 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

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 examined issues such as control, autonomy, choice and decision making. We asked agencies to write a story about each person that they support and 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

In addition to the stories of abuse at Woodlands, what came to light during the creation of the art project *From the Inside/OUT!* 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 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, and 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 had cemeteries that were desecrated, and there are several projects underway to restore them.

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

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

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).