

INSTITUTION WATCH

SPRING 2007
Volume 3, No. 1

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

This is a newsletter written and produced by the People First of Canada-CACL Joint Task Force on Deinstitutionalization. For more information, contact Don Gallant at (416) 661-9611 or Shelley Rattai at (204) 784-7362.



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MAY 2007

MESSAGE FROM THE TASK FORCE

view institutionalization of persons with intellectual disabilities as an acceptable option. As is noted in this and previous editions of Institution Watch, at least five provincial jurisdictions continue to support, both financially and philosophically, the continued institutionalization of persons with intellectual disabilities. The Task Force continues to hear stories from individuals and families who are not provided with the necessary supports (both planning and financial) that will enable a valued contributing and participating presence in community. Individuals and families continue to encounter waiting lists, service ceilings, intrusive personal and financial assessments, and the provision of inadequate supports to enable real choice and empowerment.

The edition of IW does provide however some indication of progress with respect to institutional closures. Provincial updates from Manitoba, Saskatchewan and Alberta all reveal that individuals are in fact leaving the institutions in these provinces, and that new admissions are rare. While the rate of 'discharge' is certainly far less

With the publication of this edition of Institution Watch also comes the reminder that despite the efforts of many self advocates, families, and community organizations, there are still governments and policy makers within this country that

"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



Richard Ruston and Norm McLeod, Task Force Co-chairs

**FOR TO BE FREE IS NOT MERELY
TO CAST OFF ONE'S CHAINS,
BUT TO LIVE IN A WAY THAT
RESPECTS AND ENHANCES THE
FREEDOM OF OTHERS.**

Nelson Mandela

that what the Task Force would reasonably expect these developments are indeed encouraging. The continued closures plans in Ontario and the commitment by the Ontario government to resist any attempts to derail the closure process is also reason for optimism.

ONTARIO UPDATE

**Submitted by
Gordon Kyle,
Community Living
Ontario**

Chocolate bars and Institutional Closure

As we all know, it is the things that we don't consider that can most threaten our carefully laid plans. Who would have thought that chocolate bars and deinstitutionalization have anything to do with each other? Nevertheless, when the Hershey chocolate factory in Smith Falls Ontario recently announced that it would be closing its doors, concerned members of the community rushed forward to demand that the government rethink its plans to close Rideau Regional Centre, an institution in that same community slated for closure in 2009. Hershey and Rideau Regional Centre are the two largest employers in this small community an hour southwest of Ottawa, each employing over 600 people.

The calls for rethinking the closure have come from members of the public, municipal and union leaders and from the leader of the provincial opposition party, John Tory who has been quoted in the media as wanting to see the institution reconfigured as a centre for dealing with specialized disability support. Community Living Ontario has gone on record and called on government to hold to its closure plans. The Association has reminded government that the closure of the facility will not, in fact, significantly reduce the number of jobs in the region but will shift the jobs to support positions in community organizations, most of which are located in the southwest region of the province where the facility is located. Further, the vacating of the Rideau facility opens the door to redevelopment of the sight to some other government or public use that can bring new employment to that community.

The provincial government has been firm in its commitment to proceed with the closure, responding to the calls for a rethinking of the plan by largely echoing Community Living's position that the closure opens new opportunities for redevelopment. We have had the good fortune that the current Minister of Economic Development, the person responsible for the government's response to this matter, is Sandra Pupatello, who, as Minister of Community and Social Services in 2004, launched the current closure initiative. We have no doubt that the current government will hold firm on its commitment to close this and the other two remaining institutions in the province

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by the target date of 2009. The only unknown in this regard is what might happen should the government change on October 10, when Ontario holds its next provincial election. Community Living Ontario is currently in discussions with the leader of the Conservative Party to clarify his position on the closure and to reconfirm his Party's long-standing policy supporting the elimination of institutions as an option in Ontario.

The closure of the last 3 institutions in Ontario and the plans to support the almost 1000 people in these institutions to return to the community is proceeding well. It is still expected that the process will be completed by 2009 as originally planned, despite significant delays in planning and placement caused by the 2005 legal action by families in two of the facilities aimed at stopping the initiative. As of March 31, 443 people have been supported to move to the community and plans are being developed or are completed for the remaining 522 individuals. We have heard reports, in fact, from the Southwest Regional Centre, the one facility not affected by the 2005 legal action, that the closure process could be completed next year, a year ahead of schedule.

MANITOBA UPDATE

**Submitted by
Dale Kendell
Executive Director,
Community Living
Manitoba**

Twelve individuals have moved from the Manitoba Developmental Centre in Portage La Prairie to new homes in the community. Fifteen additional people are in the process of planning options in the community. This is part of the Manitoba Government's 'accelerated pace' strategy to enable people to move. A Government Committee, with community participation, has been in place for 18 months (September 2005 – March 2007). The 12 individuals who have left have experienced solid planning, choice in where they will live and appropriate supports to assist each individual to be welcomed into a new environment. People have chosen to live in the communities of Ericksdale, Winnipeg (5), Portage, Carberry, Brandon, Flin Flon and Altona (2). Planning is underway with 15 other people who will be leaving shortly for community support in Steinbach (2), Winnipeg (7) and TBA (6).

The population of MDC is declining; since December 2004 the population has declined from 402 people to its current number of 366. During that time period it must also be noted however that 24 people have died. While the movement of even one person from MDC is great news and we applaud efforts in this respect, it is difficult to view the movement of 12 people out of the institution (in 18 months) as an 'accelerated pace'. Community Living – MB continues to call upon the Manitoba Government to reduce the MDC population by 75 persons per year until closure is achieved.

There have also been developments with respect to the Human Rights Complaint filed September 28th, 2006 involving 380 (currently 366) who reside at the Manitoba Developmental Centre – Portage La Prairie, MB. The complaint states that the Minister, the Executive Director of the Manitoba Developmental Centre, the Public Trustee and the Commissioner of the Vulnerable Persons Act are not acting in the best interests of the individuals at MDC. Community Living – Manitoba recently announced that a detailed report has been presented to the Manitoba Human Rights Commission with respect to responses received from the Minister of Family Services and Housing, the Executive Director of Manitoba Developmental Centre, the Public Trustee and the Commissioner of the Vulnerable Persons Act. These documents were received in late December 2006 and Community Living – Manitoba has now completed a process of review with our legal team of Community Living – Manitoba led by Byron Williams of the Public Interest Law Centre and Dave Wright of Aikins MacAulay & Thorvaldson.

Val Surbey, President of Community Living – MB said, ‘We expect the Human Rights Commission to proceed on the complaints in a most timely manner – people deserve freedom and an opportunity to live in the community with appropriate supports. We are discriminating against a class of people as we confine 366 people to live (then die) at Manitoba Developmental Centre. Why do some people have the right to live in the community and others are denied? We don’t need platitudes and public relations. We need action plans authorized by the Minister Gord Macintosh that enable at least 75 people per year to leave with good planning and appropriate supports.’

Surbey continues “A total of only 12 people have left the Manitoba Developmental Centre under the Province’s ‘accelerated pace’ committee from January 2005 to March 31, 2007 and plans are underway for an additional 15 individuals. These are “hooray moments” for the people who have left, but sad moments for those who remain at the Manitoba Developmental Centre.

Community Living – MB urges the Human Rights Commission to proceed with the complaint. An expert witness group is being assembled and advice is being received from the National Deinstitutionalization Task Force.

The Human Rights Commissioner is expected to appoint an investigator in May 2007. The full text of Community Living – Manitoba’s response is available to www.aclmb.ca. For more information, contact Dale Kendel at 786-1607 or Byron Williams at 985-8540.

ALBERTA UPDATE

**Submitted by
Norm McLeod**

A new committee, the Alberta Committee on Deinstitutionalization (ACD) has been formed in Alberta. The purpose of the committee is to ensure that deinstitutionalization becomes a provincial priority.

The Calgary Community Living Society (CCLS) has agreed to be the sponsor for this new committee. Sharon Cobb, President of CCLS feels that it is entirely fitting for CCLS to support this new committee. Sharon states "We have the expertise, experience and commitment to include people with developmental disabilities in our communities. Institutions are not viable alternatives. We can and must do better. People lives are at stake. Establishing this committee is one way CCLS can help other families bring their children out of institutions to live in the community".

The Alberta Committee on Deinstitutionalization includes representatives from People First of Alberta, the Alberta Association for Community Living, Regional Family Voices Network and other interested citizens. ACD will work closely with the Joint National CACL, People First Task Force on Deinstitutionalization.

In the early 1970's Michener Centre the largest institution in the province housed appropriately 2400 people with intellectual disabilities. As of March 31, 2007 there are 300 people living at Michener. Wayne Morrow, Project Director at Michener Centre projects that 12 people will be supported to move to the community this year. Wayne also indicated that during the last three years there has been only one admission. The admission was due to a Court Order, which Michener Centre legally had to accept.

ACD has also asked government officials to provide information about the number of people and the operating cost for the other four provincial institutions. Watch for this information update in the next publication of Institutional Watch.

SASKATCHEWAN UPDATE

**Submitted by
Laurie Larson and Bill
Hogarth, Co-chairs
Deinstitutionalization
Coalition of Saskatchewan
(DCS)**

There remains some very strong opposition to our efforts to bring the facts surrounding deinstitutionalization to people in SK and to work for permanent closure of institutions in this province. This opposition is coming from a small but vocal group. The facts are clear, every individual regardless of the level of support they require, can and should be supported in homes of their own in the community. These facts are undeniable. This has meant, that in order to oppose deinstitutionalization, the issue must be twisted and manipulated in order to create confusion and fear. This is the tactic that has been

taken by those opposed to institutional closure and is something we will actively continue to counter with the truth.

We continue to attempt to engage senior government officials in discussions about deinstitutionalization but to this point they have not agreed to meet with the DCS.

Community Living Division (CLD) has an internal “transition team” which has been in place for a number of years and who work to move people out of Valley View Centre and back to the community. While this team has been in place for a number of years now, they had not succeeded in moving many people out of the institution. In this past year however, they have been much more successful. It is our belief that our efforts to increase awareness about deinstitutionalization and to push for the closure of VVC has lead to this increased activity and made it possible for some people to leave VVC.

In the process of transitioning people back to community, VVC has been able to close one “cottage” (ward). They have also started to demolish unused buildings on the VVC site that are no longer needed due to the continued downsizing of the institution. We see both these things as positive developments in moving towards permanent closure of VVC. One of the goals of the DCS is to ensure that SACL has a place on CLD’s transition team in order to help guide the creation of the new supports and to make sure that each and every transition is planned and supported to ensure success. The DCS will continue to work towards this goal and will press the government to meet and discuss this.

We remain committed to continuing in our efforts to educate people about the realities of deinstitutionalization and to push for the creation of new, innovative, individually funded options as an alternative to the institutional care being provided at this time.

Our forum on deinstitutionalization “Freedom, Reconciliation and Community Living for All” is scheduled for May 2, 2007 in Saskatoon and this will provide yet another opportunity to raise awareness and to present the facts that it is imperative to move beyond the options of the past and into what we know to be not only right but very much possible.

**WORLD CAFÉ
FORUM
Nova Scotia**

A World Café forum was hosted recently by Nova Scotia Association for Community Living, People First Nova Scotia and the Disabled Persons Commission to discuss how Nova Scotians can work together to assure the best quality of life for people with an intellectual disability.

The purpose of this forum was to bring together diverse groups to

explore how advocacy organizations, government, service providers, families, people with an intellectual disability and interested others can effectively work collaboratively to address deinstitutionalization in ways that meet the needs and address the concerns of all involved.

“This forum couldn’t come at a better time for us in Nova Scotia,” remarked John Cox from People First Nova Scotia who opened the forum. It is the first time that people with two very diverse opinions are in the same room, working towards the same issues. There is no doubt in my mind that there are some people in this room who believe that an institution is the right place for Nova Scotians labeled with an intellectual disability. There is no doubt in my mind that there are some people in this room who believe that all Nova Scotians labeled with an intellectual disability should be supported appropriately in their communities. No matter what your opinion is, there is no doubt in my mind that everyone in this room believes that people labeled with an intellectual disability need to be adequately supported.”

Forty five people attended the World Café, they contributed and discussed what their concerns and fears were, what their shared understanding of the meaning of “home”, and most importantly, how they could work together to chart a course forward to ensure the best quality of life for people with intellectual disabilities.

These were some of the ideas put forward:

- Garner more political will
- Need to go to the decision makers because they won’t come to us...change strategy
- Need to record the “history” of this issue, what has happened in the past and how it has brought us to current reality-compile the knowledge. There was a real concern that the history is being lost.
- The focus needs to be at the grassroots level-enlist more people and demand that politicians respond...especially since politicians change so frequently
- Need to use different tactics to build community collective capacity
- Ask the right questions...cross disciplines
- “Adopt an MLA “ concept”
- Create social and political action...community networks getting involved and making a difference
- Media have a role to play...need to keep mobilizing and keep it front and center

There will be two more forums held in the future to build upon the action steps that were suggested.

YOU AND I

By Elaine Popovich

I am a resident.

You reside.

I am admitted.

You move in.

I have behavior problems.

You are rude.

I am non-compliant.

You don't like being told what to do.

When I ask you out to dinner, it is an outing.

When you ask someone out, it is a date.

I don't know how many people have read the progress notes people write about me.

I don't even know what's in there.

You didn't speak to your best friend for months after she read your journal.

I make mistakes during my check writing program. Someday I might get a bank account.

You forgot to record some withdrawals from your account. The bank called to remind you.

I wanted to talk to the nice looking person behind us at the grocery store. I was told it was inappropriate to talk to strangers.

You met your spouse in the produce department. He couldn't find the bean sprouts.

I celebrated my birthday yesterday with five other residents and two staff members.

I hope my family sends a card.

Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounded wonderful.

My case manager sends a report every month to my guardian. It says everything I did wrong and some things I did right.

You're still mad at your sister for calling your mom after you got a speeding ticket.

I am on a special diet because I am five pounds over my ideal body weight.

Your doctor gave up telling you.

I am learning household skills.

You hate housework.

I am learning leisure skills.

Your shirt says you are a 'couch potato'.

After I do my budget program tonight, I might get to go to McDonald's if I have enough money.

You were glad the new French restaurant took your charge card.

My case manager, psychologist, RN, occupational therapist, physical therapist, nutritionist and house staff set goals for me next year.

You haven't decided what you want out of life.

Someday I will be discharged, Maybe.

You will move onward and upward.

by Elaine Popovich and the Reece Community Living Endeavor
www.reeceendeavor.org (Midland, MI, USA)

PEOPLE FIRST FREEDOM TOUR

**Submitted by:
Josée Boulanger**

This summer **Self-Advocates Hit the Road!** From August 18th-31st, 2007 we will be traveling the Prairies to collect testimonies from institution survivors and organizing events with People First of Alberta, People First of Saskatchewan and

People First of Manitoba to raise awareness about the right of all people to live in the community.

The People First Freedom Project started on a cold February day when self-advocates and their allies assembled at the Manitoba Legislature to protest the government's decision to invest 40 million dollars into the Manitoba Developmental Centre (MDC), an institution where nearly 400 people labelled with an intellectual disability are being warehoused.

I was there with my video camera and interviewed self-advocates from Ontario, Saskatchewan, New Brunswick and Manitoba. They all had very strong opinions and important stories to tell. A year later, I visited People First members of Winnipeg and recognized some of the self-advocates I had interviewed shortly after the protest. I introduced myself as a community video facilitator and asked them if they would be interested in making videos. They responded with great enthusiasm and dedication.

Since then, I have been working collaboratively with five members of People First of Winnipeg: Valerie Wolbert, David Weremy, Kevin Johnson, Susie Weizsmann and Mark Blanchette to produce five video self-portraits, the Free Our Friends Radio Show, The People First Freedom Tour and a film documenting these experiences of self-advocacy and of institutional survival across the Prairies.

The project has received funding by People First of Canada and The National Film Board of Canada.

The Freedom Tour will be making stops in Winnipeg (where we begin), Portage La Prairie, Moose Jaw, Red Deer and Edmonton (our last stop). Contact us if you would like to get involved in the Freedom Tour:

Project Coordinator: Josée Boulanger
Cell: 1-204-998-6846
e-mail: freedom.tour@yahoo.ca
Website: www.mts.net/~joseeb/index.html
Toll-free: 1-866-854-8915 (People First of Canada Office)

THEN AND NOW

By Roy Skoreyko
as told to Norm McLeod

We sit with Roy in a coffee shop in downtown Edmonton talking about life. We talk politics. He likes Stephane Dion and hopes the new Liberal leader will bring changes to the environment and the federal government. When asked about Alberta's Premier Stelmack; "He's a good Ukrainian!" Roy is full of jokes, has a great sense of humor, is quick to laugh, and makes clever comments that have us all smiling. It's hard to image Roy growing up in Red Deer's Michener Centre.

"I've been out of Michener for about 30 years," says Roy. "When I was 10, I was classified as slow learner and was sent to the provincial training school. We were a poor family, we lived in Elk Point on a farm near St. Paul. I have a younger brother who was also classified as slow and he went to Winifred Stewart School." In those days parents took the advice from doctors and Roy's family doctor advised that he be moved away from his family after grade one. "There was a school in Michener that I went to," says Roy. I didn't go far in school because they wanted us to work inside the centre. We were working with the garden crew, laundry and kitchen." Rather than going to school like other kids his age, Roy spent his summers hoeing and picking weeds and in working in the laundry through the winter."

He talks about abuse and kids getting beat-up by each other and by staff, but it seems like the constant control and lack of freedom had a stronger affect on him. "It was tough times there because we didn't have the freedom that we have now," says Roy. "We had to line up to go for meals, the day room was always locked so we couldn't leave. We had to sit on the floor when we watched TV or listened to the radio. We had to line up naked to go for a shower and everyone went in to one big area to shower. There was no privacy. To sleep it was dormitory style, beds were all lined up and we had to share with a bunch of other people."

"We didn't have areas for keeping our own belongings. We had toothbrushes and a few cloths on a shelf; a couple feet big. They kept our clothes and issued us with ward clothes. The only time we got to wear clothes our parents bought us was when we were going home. If your name wasn't on them you wouldn't keep them."

It's hard to imagine how hard the lack of freedom must have been on Roy as a boy. He pauses in the midst of describing bathrooms with no doors and the toilets sitting in the middle of the floor to make a couple of quick funny comments to lighten the mood.

Then Roy tells the story of how they were told they were going on a trip, instead they were taken to the infirmary and sterilized. "It was never explained to us, they just said we were going on a trip and instead we were sterilized."

But the transition from Michener Centre to the community wasn't an easy one for Roy. "It was for me when I moved out of Michener because everyone wanted to do things for me. The hardest part was doing things for myself because I had people doing things for me all my life. I had to learn how to do my own banking and pay bills, cooking, laundry. I had to learn how to stand up for myself." Now he's standing up for others too.

"I got more involved by sitting on boards and began speaking and helping others speak, self advocacy, along with AACL and people in Toronto have really helped me. People like Bruce Uditsky and Sandra Mak helped teach me how to speak out and advocate for myself. We all have dreams and I encourage others to speak for themselves."

Roy was the first person with a disability to sit on one of Alberta's Persons with Developmental Disabilities Community Boards. "When I sat on the PDD board I wasn't a board member at first, I was a board intern. I was part of the board but didn't have a voting right, because members had to be appointed by the Minister." Now there are other self-advocates who regularly sit on PDD boards. "I gave my advice on issues, sometimes they were confidential matters, budgets and things. We made a lot of tough decisions and we had to answer to the Minister. I was surprised by how many people had a say in decisions."

"When I moved out of Michener I made two Promises, to stand up for the rights of self advocates who are living in the community and to protect the rights of those still living in institutions. I would like to see the institutions closed across the country. We have a plan, we have a strong voice from People First groups that are in willing to do something about it," says Roy. "I consider self advocates as my family. I slept in the same dorms as them; I ate the same meals as them. I think that it doesn't matter if self-advocates have to work with government officials to make the system work. We can complain and gripe but we have to go there and look them in the face and ask for help. Government officials are slowly learning that it can be different. You can't forget how far we've come."

"When I leave this world I want people to remember me for who I am. I'm a person first. We all have some kind of disability. I want people to remember me for what I've done."

CALL FOR CONTRIBUTIONS

We encourage you to submit stories, Provincial/Territorial updates, pictures and/or personal perspectives on this issue. Please send all contributions directly to Don Gallant at dgallant@nl.rogers.com for publication in our next edition (due out in September 2007).

ACKNOWLEDGEMENTS

CACL and People First of Canada gratefully acknowledge the Government of Canada (Human Resources and Social Development – Social Development Partnerships Program) for supporting our national Community Inclusion Initiative.



On May 2, 2007, in Regina, Saskatchewan, People First of Saskatchewan held a rally in front of the provincial legislative building to raise awareness and voice their concerns regarding people currently living in Valley View Centre in Moose Jaw, SK. The PFC CACL Joint Task Force on Deinstitutionalization was pleased to join them in giving voice to the collective demand that Valley View Centre be closed as soon as possible and that all persons living there be assisted in moving to the community.

