

INSTITUTION WATCH

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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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MESSAGE FROM THE TASK FORCE

Canada persons with intellectual disabilities have still not secured the right to live in community. We remain hopeful however that the signing of this Convention, a legally binding document which affirms the right of persons with disabilities to live in community, will serve as additional moral and legal imperative for governments across this country to take action and assist persons still trapped in institutions to take their rightful place in community. There are many compelling reasons to do this — there are no reasons not to!

The joint PFC – CACL Task Force on Deinstitutionalization has in recent months assumed an additional responsibility. The Task Force, acting on behalf of both the Canadian Association for Community Living and People First of Canada will now play a leadership role in developing a national plan on Deinstitutionalization. This role will witness increased coordination across the various activities underway in provinces and territories with regard to deinstitutionalization, increased support of the Task Force to these activities and ultimately a more effective collaborative

As we join with people around the world in celebrating the passage of the Convention on the Rights of Persons with Disabilities by the United Nations General Assembly, we are saddened by the realization that in a country as progressive and affluent as

“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

result of our various efforts across the country. The Task Force has changed its membership to better reflect input from the provinces involved in deinstitutionalization efforts. We also anticipate that this new role will see a greater presence of the Task Force in provinces throughout the coming year.

As we enter a new year we hope that in 2007 we will make progress toward our goal of full deinstitutionalization in Canada. A year which will finally see the practice of placing persons with intellectual disabilities in institutions cease; a year in which all provincial governments, but in particular those in Alberta, Manitoba, Saskatchewan, Ontario, Nova Scotia and PEI, will see the wisdom to assisting people to live in community; a year in which we all, as Canadians, demand that our fellow citizens with intellectual disabilities be provided the appropriate level of supports and services so that they too may join us in living in community.

DEINSTITUTIONALIZATION: GOOD SOCIAL POLICY!

Often times demands for deinstitutionalization are dismissed as being too idealistic; not practical; a view held only by a few radical parents and well intentioned advocacy

organizations out to destroy a perfectly good system. Opponents to deinstitutionalization assert that persons with intellectual disabilities (especially those labeled as 'severe') are better served in institutions, that they cannot be supported in the community, and that institutions represent the only appropriate place in which they can and should live.

What those opposed to deinstitutionalization fail to acknowledge (or accept) is that evidence gathered during the past 25 years clearly demonstrates that community living is superior to institutional care. They fail to recognize that these efforts have *proven* that persons with intellectual disabilities are better supported in the community.

When one suspends the impassioned arguments, what do we really know about how people with intellectual disabilities who have left institutions fare in community? To begin we know that 'the sum total of rigorous studies over a 25 year period provides conclusive evidence of the superiority of community living'. An analysis of research findings (Conroy 2006) based on deinstitutionalization efforts implemented in the U.S. over the past three decades provides the following conclusions:

Research Shows Multiple Benefits of Community Placement: Twenty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The literature is remarkably consistent in this area. Their qualities of life are enhanced, they are more

TASK FORCE MEMBERS

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independent, they display less challenging behavior, their homes are more pleasant, and their families believe that they are far “better off” than they were in institutions.

Deinstitutionalization in Developmental Disabilities Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field: The deinstitutionalization of nearly 100,000 American citizens with developmental disabilities has been highly successful. This is a very different experience from the nation’s failure to support people with mental illness who have left mental health institutions.

Family Attitudes Change Dramatically: Families (parents, siblings, other relatives, guardians, friends) of people living in institutions overwhelmingly support the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people have moved to the community the families’ attitudes change dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement have become ardent supporters of community living once it has been experienced.

The Theory of the “Must Stay” Group is Not Supported: The classic four reasons given for keeping people in large segregated settings (severe disability, challenging behavior, medical fragility, and advanced age) have been convincingly discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 25 years, and by the fact that 10 states are now entirely free of public institutions as an option.

Community Support Systems are more Cost Effective than Institutional Systems: All studies published thus far are consistent. Community service models are less costly than institutional models.

Community Living is Not Without Problems, and Requires Protections: It is clear that the overwhelming majority of people can be expected to have very positive experiences with community living. Yet it must be recognized that a small proportion of people will have serious difficulties in the community. There are certain protections that appear to be very important for people who move from institution to community and include: support coordination, person-centered planning, and quality assurance.

The Canadian experience, while not as well documented as in the U.S., shows similar outcomes (and conclusions) as those noted above. Thousands of persons have left institutions and now live in community. Several provinces no longer have institutions for persons with intellectual disabilities. Perhaps it is time that public policy makers were held accountable for their decision to retain institutions and that we were told of the real reasons for these decisions. Could it

**“NO, I HAVE NOT
COMMITTED A CRIME —
WELL, I GUESS I HAVE. I WAS
BORN WITH A DISABILITY”**
*Peter Park, in response to why he
refers to his years in an institution
as “incarceration”.*

be that protecting the jobs of those working in institutions is more important than the lives of those living there?

In a time where all governments are demanding increased accountability and transparency in the expenditure of public funds, where the demand is for evidence based best practice as the target for public investment, why do our public dollars continue to support an institutional system that has been shown to be inferior to a community based system? Perhaps it is time that these policy makers actually reviewed the research and acted accordingly!

“BUT MOST IMPORTANT OF ALL IS FOR US TO CELEBRATE THE RESILIENCE OF THOSE THOUSANDS OF PEOPLE, WHO AFTER YEARS OF CONFINEMENT IN THE INSTITUTIONS OF THIS PROVINCE ARE ABLE TO ADAPT TO A NEW LIFE IN THE COMMUNITY SO READILY AND SO ENTHUSIASTICALLY. LET US CELEBRATE HOW WILLING THEY ARE TO FORGIVE US AS A SOCIETY FOR DOING WHAT WE DID TO THEM THOSE MANY YEARS AGO, TELLING THEM THAT THEY DID NOT BELONG WITH THEIR FAMILIES AND FRIENDS IN THE COMMUNITY”.

*Orville Endicott
Closing Institutions, Opening
Communities September 2006*

INSTITUTIONS STILL REMAIN

Many Canadian provinces and territories have closed institutions for persons with intellectual disabilities. Ontario is in the process of closing its remaining three large facilities (population of approximately 1,000 people — target closure date of 2009). The provinces listed below however continue to maintain a network of institutions with no plans for closure in the immediate future. Apparently the public policy makers in these provinces have chosen to ignore the volumes of evidence indicating the superiority of community living and continue to expend public funds on an outdated and inferior system. Individuals with intellectual disabilities, their families and advocacy organizations continue to ask why!

ALBERTA: 6 large institutions – 527 people

SASKATCHEWAN: 3 large institutions – 413 people

MANITOBA: 2 large institutions – 580 people

QUEBEC: 3 large institutions – 525 people

NOVA SCOTIA: 12 large institutions – 696 people

PRINCE EDWARD ISLAND: 2 large institutions – 37 people

NOVA SCOTIA UPDATE

**Submitted by
Mary Rothman, Nova
Scotia Association for
Community Living**

Nova Scotia is institutionalizing more of its citizens. On November 16th, 2006, the government of Nova Scotia announced the creation of another institution. This is happening in a province of less than a million people and one that already has almost 700 people living in facilities called either Adult Rehabilitation Centres or Adult Residential Centres. This fact needs to be put into perspective. If the same ratio were used for other provinces, Ontario would have over 9000 people in institutions and British Columbia would have 3211. We know that is not the case.

Nova Scotia knows how to support people in their own communities. There are thousands of people living in community who used to be institutionalized. We began closing our institutions in the late seventies and we did it well. Apparently this is no longer government policy.

The new institution will house at least 25 people. We are told some will be people from other facilities including the forensic unit. We are told that they will be “complicated cases”. We are told that some will have intellectual disabilities and some will have long term mental health issues. The new facility will actually be created in a building that is now empty. It used to be a multi purpose community health center. It has been rejected by the Minister responsible for what we call Access Centres that are places where you go to get your identification papers, register your car, get a driver’s license etc., because it is not convenient for people to get to; no sidewalks, no bus service and not enough parking. It sits beside the off ramp of a major highway. However, it is deemed suitable to house people with disabilities.

‘THE ONLY DIFFERENCE BETWEEN MY KIDS AND PEOPLE LIVING IN INSTITUTIONS IS THE YEAR THEY WERE BORN. MY SONS ARE NO MORE DESERVING OF A LIFE IN THE COMMUNITY THAN THOSE PEOPLE STILL INSIDE VALLEY VIEW CENTRE.’

Laurie Larson, Parent and Chair of the Deinstitutionalization Coalition of Saskatchewan

Within two working days of the announcement, NSACL and People First held a press conference attended by over 150 people. Nova Scotians are upset. Many have expressed their feelings to the media, the Minister and their own MLA’s. NSACL and People First Nova Scotia met briefly with the Minister and have been promised a longer meeting soon. We hope to begin fruitful discussions with government officials shortly.

In the meantime, individuals who once lived in institutions are offering to tell their stories. Families who now know how much richer their loved ones’ lives are now that they live in the community are offering to tell their stories. Service providers who support people in the community who used to be institutionalized are offering to tell their stories. People who once worked in an institution are offering to tell their stories. And we continue to hear from dismayed Canadians from coast to coast to coast.

ONTARIO UPDATE

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

Work continues in Ontario towards the planned closure of the last three large institutions in the province for people who have an intellectual disability. The target date for closure remains March 2009, despite delays in planning as a result of court actions brought by families in two of the facilities last year. The court action resulted in a finding that the government had the authority to proceed with the closure of the facilities and clarified the rights of

families to be involved in decisions about where people moved when they left the institution. Despite these findings, some families continue to resist the closures and are very actively trying to change the decision of the government to close.

The efforts of some families to oppose the closures include an ongoing and intensive media campaign, complaints to the Provincial Ombudsman, and appeals to the government opposition parties for support in resisting the closures. We have been disappointed of late to hear suggestions from the leader of the official opposition, Conservative Leader, John Tory, that he might favour some form of redevelopment of one of the institution sites to allow some people to continue living there. Community Living Ontario is in the process of setting up a meeting with the Opposition Leader to discuss our concerns about this proposal. Ontario will be having a provincial election on October 4th 2007, so this is a matter of some concern for us given the possibility of a change of government before the closure process is completed.

So far almost 300 of the 1,000 people scheduled to leave the three institutions have been planned for.

Another significant concern with respect to institutionalization in Ontario is the recent release of government protocols for the placement of people who have an intellectual disability into long-term care facilities. The government insists that the protocols are designed simply to ensure that, for the small number of people who might require access to these facilities, they receive any additional support that they might need. The protocols contain, however, specific direction to "developmental service providers to consider the transition of individuals with increasing health care needs that they are currently supporting residentially into an appropriate long-term care home setting". They go on to state that "This will create developmental services community-based capacity to accommodate residents moving from the developmental services facilities." Community Living Ontario is alarmed that government is suggesting that service providers have the authority to institutionalize people and that this is being done in order to create space in community services. We have arranged talks with the government in the new year to review the protocols.

Over the past few years, Ontario has experienced a tremendous over-capacity in the number of beds in our long-term care system as a result of large investments in the sector by the previous government. The vast majority of the new capacity has been in the for profit long-term care sector. We have expressed concern that people who have intellectual disabilities might be inappropriately directed to these facilities to fill the beds. Recent statistics on populations within long-term care in Ontario are alarming, showing that more than 1,500 people who have an intellectual disability are living in these facilities.

Our work to have the protocols withdrawn and to address the inappropriate placement of people in long-term care facilities will represent a significant portion of our work on deinstitutionalization over the coming months.

MANITOBA UPDATE

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

Two years after the announcement by Christine Melnick, former Minister of Family Services and Housing, to invest \$40 million in the redevelopment of Manitoba Development Centre no construction has gone forward.

The new Minister, the Honourable Gord Macintosh, has offered a “fresh set of eyes” to the issue, but 90 days after the Human Rights complaint was filed, the Provincial Government lawyers have asked for a further extension to respond to the 34 issues raised in the complaint. A response is expected sometime in January 2007.

HUMAN RIGHTS COMPLAINT FILED AGAINST THE MANITOBA GOVERNMENT

Manitoba ACL has filed an official complaint with the Manitoba Human Rights Commission today. The human rights complaint was made on behalf of the 380 people who live at the Manitoba Developmental Centre in Portage La Prairie, Manitoba. The 380 people live with an intellectual disability. The complaint comes after many attempts over the past 18 months by Community Living - Manitoba to negotiate with the Manitoba Government community living alternatives to the continued institutionalization of the 380 people. The complaint outlines that Manitoba Government has taken the wrong direction on services for people with intellectual disabilities. It is filed on behalf of those people living at MDC and with support of the many agencies Community Living-Manitoba works and plans with throughout the province: service agencies, People First of Manitoba, People First of Canada, and coalitions of social justice groups and families.

The story begins with the December 2004 Government announcement to spend \$40 million on renovating and rebuilding the aging Portage La Prairie institution. This action flies in the face of the Government's own 2001 “Full Citizenship — A Manitoba Strategy on Disability” Report which acknowledges the human rights of all, the right to be free in the community and not be locked up under the rigid systems of an institution. This sort of housing is contrary to social policy trends in Canada today where the closure of institutions is a recognized and accepted trend.

Keeping people in institutions is a failure and violation of human rights. The Manitoba Government has failed in not following its own

policy direction nor creating policy to bring people out of institutions. Keeping individuals in MDC also fails to utilize the expertise and considerable talents of 106 community organizations who would create options and enable community living if Government redirected funds and asked for their involvement. The Manitoba Government has also failed to utilize the talents of staff at MDC to create community options for people.

The Human Rights complaint seeks to prove that institutional options, no matter how presented by government or anyone, do NOT:

- advance rights of individuals
- create participation in the community members
- develop relationships with the community
- provide and promote respect, dignity and self-determination and daily choices in most areas of living. In fact they create control over another person's life
- promote individuals in the spirit of the principles of the Vulnerable Persons Act.
- acknowledge that a wide range of options currently exist and others could be developed for the 380 individuals who currently reside at MDC in Portage.

SASKATCHEWAN UPDATE

**Submitted by
Laurie Laison, Chair of the
Deinstitutionalization
Coalition of Saskatchewan**

individuals with intellectual disabilities, regardless of their level of support needs, in inclusive homes within the community.

The Deinstitutionalization Coalition of Saskatchewan (DCS) has had a full few months as we have worked to raise the profile of deinstitutionalization in our province, to create discussion around this issue, and to push for new, innovative solutions for supporting all

Some of our awareness activities include:

- distributing copies of *Hear My Voice*, (the Alberta Association for Community Living's book on survivors of institutions) to politicians who had expressed an interest in deinstitutionalization
- distributing copies of the Summer 2006 edition of *Institution Watch* to all MP's and MLA's in the province
- publishing two articles on deinstitutionalization in the Fall 2006 issue of *Dialect* (SACL's newsletter)
- developing a DCS web page, which will be updated and supplemented with information and resources on an ongoing basis (link to this page www.sacl.org)
- developing and distributing, with SACL, a fact sheet to address questions that have arisen around this issue

The most exciting activity for the DCS in the past few months has been the development of a Special Edition of Dialect focusing on deinstitutionalization. The Special Edition includes articles on citizenship and protection, the human rights complaint filed against the government of Manitoba, and most importantly, powerful stories of the experiences of former residents, parents and a former staff member of Valley View Centre (VVC), Saskatchewan's largest remaining institution. This Special Edition of Dialect will be distributed early in January 2007 to 4700 individuals, organizations, government, service providers, schools and members of the public.

Deinstitutionalization is not a new concept. Efforts to move away from congregate care have been occurring worldwide for many years. Countries such as Sweden and more recently New Zealand have completely closed all their institutions and some provinces in Canada have done the same. The fact that institutions remain in Saskatchewan is not because they are necessary for "some" individuals but rather because we have not yet been able to move past the institutional mindset that was created many decades ago. Research and experience has proven, time and again, that every individual can be successfully included in our society if only governments will commit the resources to creating individualized, person-centred supports and making them available to everyone. Our government in Saskatchewan has committed in recent years to no new admittance to VVC, and in doing so have proven that alternatives can and do exist. It is time to take that final step and reinvest in the community so that all individuals who still remain in our institutions can be afforded the same opportunities and rights that others with the same support needs already receive in this province.

The DCS has been successful in creating discussion around deinstitutionalization in Saskatchewan in the past two months. It is very apparent from these discussions that there remains many misconceptions and fear around deinstitutionalization. The DCS remains committed to presenting the facts and advocating for the services and supports required to ensure a successful transition into the community for all individuals who remain in institutions.

**PLANNING IS UNDERWAY
FOR A DEINSTITUTIONALIZATION
FORUM TO BE HELD IN
SASKATOON ON MAY 3, 2007.
MORE INFORMATION ON THIS
FORUM WILL BE POSTED ON
THE DCS WEB PAGE AS IT
BECOMES AVAILABLE.**

**IN AN INSTITUTION YOUR RIGHTS
ARE TAKEN AWAY AND YOU ARE
DEVALUED. IT IS TIME TO TAKE A
STEP AHEAD TO INCLUSION AND
HAVE ALL PEOPLE BROUGHT INTO
COMMUNITY WITH SUPPORTS.**

*Shane Haddad, President - People First
of Canada*

MY VISIT TO MDC

**Kevin Johnson,
Vice President, People First
of Manitoba**

I was invited to attend a visit to MDC by People First of Canada as a representative from Manitoba.

While I was happy to be asked, I remember the week before we went, feeling a lot of emotion about going. I had been there before. I played in a hockey tournament there a long time ago. I had also visited there with some People First of Manitoba members. We didn't have a tour then, we only saw the gym as there was a social evening that we attended. A few months prior to this visit, I went with a friend of mine and his support worker to visit someone who lives there. But this time, with PFC, was the first time I had a full tour and really saw what goes on inside.

When we got there, we were taken into a board room where we met the Executive Director and some of her staff. She talked to us about the Centre, and the areas we were going to tour.

The first section, called high risk offenders section, or lock-up as I call it, was a ward with people who were at risk of offending or re-offending in the community. I remember they had their own rooms, I remember the staff having whistles to alert people if there was a problem somewhere. I met someone I know in there, and I felt sad for him.

We then went to the Seniors ward. The men and women are on different floors. We met a lot of really nice folks there. People were really friendly and wanting to talk to us and visit with us. I remember going into a lock-up room and wondering why they would need this room. When we asked what this room was for, the staff told us it was for people who wanted to go in there and have quiet time.

The next place we saw was the deaf/blind section. I remember going into rooms and them showing us how people knew what they had to do that day. They had a little box and in it would have their shower symbol, which told them they had to shower that day. It was neat to see how they communicated with people who have real challenges around communication.

We then went into the autism ward. We walked into that section, and a guy in a wheelchair came right up to me and grabbed my hand. I shook his hand and introduced myself to him. He introduced himself. He didn't let go of my hand. He said to me, "I want to go home." He said it over and over and over. He would not let go of my hand. He repeated over and over that he wanted to go and pack his clothes, and he wanted me to take him home. The staff came and wheeled him away, and he grabbed the doorway to stop them from taking him. At this point he was yelling, "Take me home". I will never forget him.



*Kevin Johnson, Vice
President, People First
of Manitoba*

MDC — A PERSONAL REFLECTION

**Submitted by
Diane Otterbein,
PFC Saskatchewan**

Then we went to the “medically fragile” unit. I remember feeling really stressed then. We met staff who was going to show us around. She had a cat in her office. I remember going and petting that cat, and helped calm me down. It

took a lot of anger, stress and sadness out of me. While we were walking around, that cat followed us. I was kinda taking a break from listening to the staff person, hanging back a bit, watching the cat. I was hanging out with the cat. The next thing I remember, Dianne was freaking out, trying to get out of the building. All the doors were locked and she couldn’t get out. I felt helpless. I couldn’t help her. It was horrible.

We left shortly after that, and I remember being so glad to get outside. Diane was crying, and Shelley was trying to make sure everyone was OK. I felt thankful to be out of here.

On April 18, 2006, I had the opportunity to visit the Manitoba Development Centre in Portage La Prairie, Manitoba. While a bit of time has passed since that day I can still feel the anxiety when I reflect on the visit. Every time I go to slip into the shoes I wore that day, I feel a chill. I can only describe what I saw from the viewpoint of someone who was “allowed” to leave at the end of the day. Therefore, my opinions and experience are subjective, strictly based on being an “outsider” looking in.

Upon arrival at MDC, I couldn’t imagine why such a place still exists anywhere. Have we really not moved as a society on our desire to live together in the community?

The CEO told our group that “for many of our residents, this is the only home they’ve ever known...we are their family.” My immediate reaction was to argue, since I know that simply isn’t true. A place where most if not all of the relationships are with paid staff and where you have very limited control over your own life cannot be compared to a home that you have chosen to live in with all the support you may need.

Each wing made me feel more and more light headed...the “autism wing,” the “blind and deaf wing,” the “senior’s wing.” These are the labels that the folks in each area “fit” into. Except for a few staff who were comfortable making eye contact, I got the feeling that many of the staff did not welcome our visit and were only tolerating us.

While in the autism wing, we met a fellow who asked if we could help him pack...As he told us how he would be going home the next day for the weekend, his excitement was contagious, he was quite happy to be leaving and was ready to pack, now. The reality of living

in an institution on a set schedule struck me when he was instructed to go to the lunchroom instead of packing his bag.

In my own experience, I have cared for relatives and friends who have disabilities. I can't separate meeting the person's needs from caring enough to do whatever it takes to see them live the life they choose. As I sat through the luncheon provided to us at MDC, I listened as the upper managers argued that "this is the only home some of 'these people' have ever known and if you suddenly 'dump' them into the community, they'll die because they won't know what to do." I felt sick to my stomach as I tried to imagine how desperate the families must have been in order to leave their loved ones here in the first place.

The most upsetting part of this visit for me came as I read a poem on the wall of the "unlabeled wing." Written in 1956, it was titled "The Retarded and Slow." This poem talked about how happy the children are and that despite their disability, the rest of us shouldn't feel bad about it because after all "God loves us...the retarded and slow."

Pure disbelief, shock and sadness overcame me and I began to cry as the vomit rose up to my throat. I felt weak and dizzy and thought I'd better take a step outside and get some air. I excused myself and went for the door, which was stuck. When I realized I was not stuck, rather locked in, I began to panic and bang on the door until a staff from down the hall came and let me out. I went outside and wept. I didn't have time to even process any of this before it was time to move on. As we left the wing, one of the staff turned to me and said, "Yes, it's very moving up here isn't it?" Moving, yes, but not in a good way I thought.

I can appreciate the position and the language used at the time the poem was written. However, it is derogatory, 50 years out of date and in my opinion, should be removed from the inner walls of the institution, particularly if they are trying to keep up with the times by adopting such philosophies as "The Eden Alternative" and "Gentle Teaching."

People with disabilities have every right not to be placed in an institution. It may seem easier to administer an institution than it is to support people to craft their own life in the community. But that is only because we haven't tried hard enough. All we need to do is commit.

As a parent of a child with a disability, as a sister of a person with a disability and as a friend and supporter of People First members who fight for full inclusion all over this country; I am insulted that institutions continue to receive funding and support from governments who do know better. We must teach inclusion and acceptance of diversity in our community as a way of life rather than

a reaction to the presence of people with disabilities. The old excuse, “there aren’t enough alternatives” doesn’t hold water any more.

SASKATCHEWAN’S BIG HAIRY DEAL

To raise both money and public awareness regarding deinstitutionalization, Diane Otterbein, Coordinator of People First of Saskatchewan and Shane Haddad, President of People First of Canada recently participated in a *Big Hairy Deal!* If each could raise \$500, then the other would shave their head (Diane) or beard (Shane). Each reached their target and as the photos above confirm, each followed through on their promise! All funds raised (in excess of \$3000 to date) will be used to support people who are transitioning from Valley View Centre into the community. Well done Diane and Shane!



Diane Otterbein, Coordinator of People First of Saskatchewan and Shane Haddad, President of People First of Canada

WORDS IN ACTION... WALKING THE WALK

**Submitted by
Catherine Allix, People First
of Canada**

We have all probably heard the phrase — You can talk the talk but can you walk the walk? The reason we have the saying is because we all know how easy it is to say something. You just open your mouth and let the words come out.

It’s the other part of the saying — walk the walk — that can be difficult sometimes. Putting your words in action is not always easy.

I was recently both very impressed and entertained to see two people whom I have heard talk the talk (about deinstitutionalization) many times before, but this time they were walking the walk, so to speak. What they were doing was getting their respective head and chin shaved. But this was just a small part of what they were doing and what I saw.

I saw two people show their commitment, raise awareness, and put their words into action. I saw two people do a whole lot with practically nothing — hair and scissors and an idea! I saw two people engage and inform over a hundred other people; I saw two people having fun and doing good.

Watching them made me think of other sayings about how change can be made by a single committed person – and that’s what I saw. But it also made me think of other sayings about how much power there is in numbers and how much strength there is in a group. And I could see that it takes the single power of one to add up to the collective power of many. We all can do our part. We all have to do our part. The big picture is made up of little pictures of each and every one of us to doing our part.



Catherine Allix, People First of Canada

And I thought about what I could do, how I could make a statement, how I could be a part of the bigger picture. I came up with (and discarded!) many ideas and haven't settled on one yet, but I am thinking about it...we all should be.

NEW BOOK BY PEI PEOPLE FIRST!

**Submitted by
Barb Fanning**

PEI People First made a book. It has stories of people who have an intellectual disability who live in manors and community care facilities. People in those places are seniors. The people who told their story are young. They don't have anything to do in there. Everything's for seniors. They can't get out. They can't do anything. They can't go shopping.

Our book is called "*Where we Live — A collection of stories of Islanders living in community-care and long-term care facilities.*" The book has nice pictures in it.

The Premier, the government have the book. Some people in government learned from the book.

If you would like the book email PEI People First at peifirst@isn.net or phone me, Barb, at 902 892-8989.

I HOPE

**Submitted by
Larri Solomon, former staff
Valley View Centre**

Floor paint comes in soft grey, dark grey and brick red. There must have been a good sale on that brick red paint; brick red was the color I remember on the concrete floors of the tunnels that snaked under the cottages of Valley View Centre. I walked through the tunnels everyday I worked at Valley View. The place is huge with literally miles of tunnels linking the cottages; small buildings that looked like separate little houses from the top view but resemble an ant farm from underneath.

I came to work at Valley View for the money. I would almost like to be able to tell you I was one of those "very *special* people to work there...with *those* people..." but I just can't. The reality was I was 20, newly married; my husband was a student and I was a waitress. I ate a meal each day at noon because I only had to pay half-price, and then I did my best work. If I got tips, my husband got supper. We were barely making it.

I'll never forget my interview at Valley View. I was brought into an office and told that working at Valley View was mostly "custodial." I knew what he meant by the way he said it. I said I could handle it, and I was in. I remember the starting wage was more than double what I was making as a waitress. I could breathe. I want to explain

that when I began work at Valley View, I knew nothing of institutions. I spent the first three days throwing up in the spray room. Many of the things that shocked me wouldn't perhaps shock most people who are familiar with such things. I soon toughened up.

What I remember are the grey plastic mattresses with cotton sheets, and a counterpane in pastel pink, blue, green or yellow. A plastic sheet to protect the bottom sheet and one more sheet over that, small grey plastic pillow in a cotton case and the bed is made. How people could ever get warm in a bed like that was beyond me. Some had blankets, thin, cheap things. The bed is wet, and by the dim light in the dorms, I get the person up, dry him with a towel and pull the sheets off and put them in the hamper. He shivers, naked, perched on a small piece of wood that would be a shelf between the beds if he had anything to keep on it, and continues to shiver even after I put clean pajamas on him. I soon learn to bring extra towels, because those sheets have no "absorb" in them. I learned that the hard way, by pulling the sheets off with a little too much gusto. Spending the rest of the shift soaked in someone else's urine makes for a long night. It never occurred to me at the time to wonder how people could sleep in there where, in spite of seemingly constant cleaning, the smell never really went away. I couldn't imagine lying in that bed, cold and wet; changing the beds was bad enough. I can imagine it now.

IT DOESN'T MATTER HOW MUCH YOU PRETTY THE PLACE UP, HOW MANY TIMES YOU PAINT THE TUNNELS OR EVEN GET RID OF THE TUNNELS, OR PUT NICE PICTURES ON THE WALL, IT'S STILL AN INSTITUTION. IT'S NOT A HOME AND PEOPLE SHOULD JUST ADMIT IT.

Neil Mercer, former resident of Valley View Centre

Valley View had its own hospital. I was impressed at the time. I thought it meant the place was progressive. No waiting for these folks; they got their own. Robin was a ward that housed both ambulatory (people that walk) and non-ambulatory (people that use a wheelchair) residents. One day, an ambulatory guy pushed a non-ambulatory guy into the wall; non-ambulatory guy got a deep cut on his chin and I got my first experience in hospital. I wheeled him to a clinic area. I transferred him from the wheelchair to a padded table so the doctor could stitch up the gaping cut on his chin. As the doctor busied herself out of my line of vision, I attempted to calm him. He had cerebral palsy and he was very frightened. The combination resulted in such ferocious shaking that I was afraid he'd fall off the table. The doctor asked me to hold his head steady, and I did, cupping my hands on either side of his face, and using my forearms like a splint to keep his head in place. I kept my eyes on his eyes trying to get him to look at me, to distract him.

I saw the needle first out of the corner of my eye, it looked like an awl. That startled me because, although I had never been stitched, I was pretty sure that kind of needle could not be for anesthetic. Before I could respond, the doctor forced the needle through the scar tissue on his chin and it popped up through the skin on the other side of the

cut. The guy screamed and snapped his head back; the thread snapped clean through his flesh. I jumped back, letting him go. He cried and shook. I successfully prevented him from falling off on to the floor. The doctor demanded I hold him while she continued. I refused. I asked her if she had forgotten to freeze him first. She explained. "No brain, no pain."

I refused to hold him down. She sent me away, and someone else took my place. I could hear him screaming as I first walked, and then ran away. I still can. When they brought him back to the ward he was pale, and sweating. His chin was stitched like a mask on a Halloween costume. I'm sure he took some of that punishment for me, for the inconvenience I caused her by refusing to hold him down while she stitched him without benefit of freezing. I tried not to think about what happened to him after I left the room. They got the job done. I told him I was so sorry. I was told by my supervisor that the doctor said I was not to be sent up there again, and I was reprimanded for my behaviour. I went to the CNO (Central Nursing Office), so upset by what had happened to this man. I struggled with it because she was, after all, a doctor and I wondered if they would believe me. I think they did. The man at the desk looked somewhat sympathetic, and in the gentlest way possible he told me they could replace me by morning. It was a lot tougher, he said, to replace the doctor. Over the years I made three more complaints to CNO. Each time the result was the same. Over time, I got the message.

I know there are people who say nothing bad ever happened at Valley View. I have a theory, and it's not an original idea. If you work there long enough, you get institutionalized, too. I could feel it happening to me. I began sleeping through the night again and after a time, I could even eat during my shift, provided, of course, that I didn't have to eat what they ate. Mashed potatoes with cheese sauce and bacon was a popular dish. I think peas were the vegetable, tough to tell really. Once food sits on a steam table awhile, all the green stuff smells the same. Better than breakfast, though, because oatmeal splashed with liquid laxative and sugared with prescription pills could not have been a great tasting breakfast. I fed it to them all the same and ignored the puckered up faces that very clearly told me, "You know, this breakfast *sucks*."

Under the right set of circumstances, abuse will occur. Abusers know what those circumstances are, and they seek them out. To deny that abuse occurs regularly in institutions like Valley View means it is very unlikely there is a structure in place to catch and prosecute offenders. Think about it, there were hundreds of workers at Valley View when I worked there. The interview process was less than five minutes, and even if the turnover was only 10% a year, that still meant approximately two positions were filled every week. I wonder how many thousands of people may have been on payroll over the

years. And in all that time, they managed never to hire a dud? Not once? Nobody has ever been abused at Valley View? What was put in place to prevent it? People were hired using the “warm body” recruitment method, and then, within weeks, sometimes within hours they were left alone with people who could not tell on them. Sheer staff numbers, lack of screening, and the “don’t talk, don’t tell” method of service provision indicate that abuse has to have happened at Valley View, assuming people are willing to discount first-hand accounts from people who lived there. There should be the assumption that abuse can happen, and that steps need to be taken to make sure it doesn’t happen. I believe it is impossible to eliminate abuse in an institutional setting.

To be fair, there were people employed at Valley View that really liked some of the residents, and did their best to make their lives easier. As a result some people were treated well some of the time. However, even in the best places where people are kind all the time, and all staff are right with their world and nobody has cause or reason to take out their power issues and their angst on someone who cannot defend themselves, even then institutionalization is at its very best, a place to house people with many other people. It is not a home.

I say I work better under pressure; my mom says I have no basis of comparison. I think the same thing applies when people say they like living at Valley View. Having had some involvement with the foster care system, the thing that always shocked and amazed me is no matter how badly they are treated, there were children who just wanted to go home to what they knew. Even when they knew they weren’t safe there, they just wanted to go home. I don’t know if that is what people think when they say they want to live at Valley View (when the person says it, and it is not the declaration of someone else) and I wouldn’t presume that they all think that way. The point should be considered though. How can a person make an informed choice if they don’t know what the other choices are? Isn’t the devil you know always safer than the devil you don’t know?

The meals come on steam tables and you don’t have a choice of menu or meal times. The staff who strips your clothing off and cleans you *everywhere* might be someone you never met. The television programs that you watch are chosen by someone else. The clothes you wear come up from laundry in a large hamper; who knows who wore them last. Everyone in the place you live has probably seen you naked. You live with others you did not choose to live with. You cannot lie down for a nap without specific permission and you can’t stay up late watching infomercials when you can’t sleep. You can’t sit and read the newspaper while you do your business in the bathroom. You can’t sit and do your business alone. Outings involve more people than you, and they take you to places you didn’t say you wanted to go to, you cannot have a pet, you cannot drink a beer, you

cannot have sex and any outcry against this way of living is treated as a behaviour problem and dealt with accordingly.

What happens to those people in Valley View if it does get closed down? I think it depends on the person. I don't think anyone is saying to just open the doors and say "get out and stay out." I think we need to work together to make sure that every person has the supports they need, and that we need to work collectively towards that in a way that moves this thing forward. We owe them that. I owe them that.

I still think of the people I met as residents in Valley View. I am sorry I didn't stand up then. I learned to turn my eyes down, shut my ears off and do my job. When I complained, increasingly less over the years, I was told it was just me. I was just too sensitive and I could be replaced. I accepted that at the time. The truth is I lacked the strength, the stones, really, the balls to stand up and do the right thing. My life has been without regret except for the Valley View years. That period of time stands out as the time in my life I failed an entire group of people because I valued them less than the salary I was paid. In hindsight, I sold out cheap. None of those people — not one — deserved that.

For months after I quit working at Valley View, I patted my pockets for keys to let me into my own bathroom. I got so used to the keys. Two years ago I ran into a man I met first when he lived in Valley View. He had an enormous key ring with a lot of keys on it that he wore chained to his belt loop. I asked the staff he works with what the deal was with the keys. He just carries the keys around, they said. He picks them up when he can find them, sometimes people give keys to him. He collects them, they said. They don't open anything, they said, he just keeps them. But here's the thing. When he lived at Valley View, that man depended on someone else's keys to let him in and out of the ward. Someone else's keys let him in and out of the bathroom, to the office and to wherever he was allowed to go. He learned from us that keys are really important, and all the important powerful people had them. Today, I think his collection of keys is his power. Those keys put him in the driver's seat of his own life. He carries more keys than any of us ever carry. I think I know what those keys open. I think those keys mean he can let himself in and out of his own day.

People will say because I was there 20 years ago that everything is different now. I sure hope it is. I hope there is a resident's council that meets with residents of each ward, and then takes complaints forward and gets issues addressed. I hope when staff or residents complain to CNO about abuse those complaints are followed up with an investigation. I hope people are fired, residents receive acknowledgement that they were abused, and they are supported to heal. I hope staff who blow the whistle are protected in the way the

Labour Standards Act indicates they should be protected.

I hope there is tons of education that is aimed at knowing what rights are and what abuse looks like and what you should do if you witness or experience abuse and that the residents get to attend those classes with the staff. I hope there are advocates hired by someone other than Valley View whose sole purpose and function is to ensure people who live there get their needs and wants met as they themselves define those wants and needs; that their voices are heard, and their plans get feet.

I hope informed consent is truly informed and that the people who say they want to live in Valley View have full objective information given to them about what life can be like outside of institutional living. I hope they are truly given supports to make decisions that affect their own life. I hope. I hope. I hope when someone says they want to live in the community, they have access to a support team who will make that happen, and I hope they have a farewell cake and they are wished well in their new home by the staff and management of Valley View Centre.

I hope when a doctor abuses or neglects someone with a disability, that person knows to call the Human Rights Commission. That call is the second phone call made — right after that individual calls someone to find out how to write a letter to complain about the doctor, and right before the doctor is suspended pending an investigation. I hope every resident gets their own underwear and toothbrush, every day, on every ward, all of the time. I hope there have been changes. I hope the residents were involved in making those changes. I hope. I hope. I hope.

**LANDMARK UN
CONVENTION
ON THE RIGHTS
OF PEOPLE WITH
DISABILITIES
ADOPTED**

In December 2001, United Nations General Assembly resolution 56/168 established an Ad Hoc Committee “to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development.” CACL was accredited to the Ad Hoc Committee at its Second session (June 2003) and has participated in all subsequent sessions.

On December 13, 2006, the United Nations General Assembly formally adopted the UN Convention on the Rights of Persons with

Disabilities. The Convention, the first of the 21st Century, is the only legally binding international instrument to focus explicitly on the rights of persons with disabilities. The Convention advances the rights of persons with disabilities and marks an international move towards respecting these rights and taking measures to ensure the full inclusion of persons with disabilities and their families.

The Convention was adopted shortly before 11am and was greeted with loud applause. Member states were given an opportunity to speak before and after the vote to clarify their positions on the Convention. The majority of these statements were positive. Although NGOs are usually not permitted to address the General Assembly, an exception was made for this meeting. The President of the General Assembly suspended the formal portion of the session to enable two speakers to speak on behalf of the International Disability Caucus.

In celebrating the adoption of this historic Convention, CACL issued the following press release in regards to the Convention adoption.

Successes for Persons with Intellectual Disabilities and their Families

There is much to praise and celebrate with the Convention – including the recognition of supported decision-making in the article on legal capacity. The Convention will be the first legally binding document that will secure, among other things, the right to use support to make decisions and exercise legal capacity, the right to live in the community, and the right to inclusive education.

We are particularly pleased to confirm that the role of families and their need for support have also been recognized in the Convention. In addition to references in the Convention text about providing support to families, an excellent paragraph recognizing the role of families has been included in the preamble.

The paragraph reads as follows: Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the state, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.

States will now have the opportunity to sign and ratify the Convention. States must ensure their national laws are in compliance with the Convention prior to ratification. Twenty States must ratify the Convention before it comes into force. CACL is urging the Federal Government to be among the first countries to sign and ratify the Convention. The text of the Convention is available on the UN website at: www.un.org/esa/socdev/enable

DOWN THERE YOU COULDN'T GO OUT. YOU HAD TO HAVE STAFF WITH YOU ALL THE TIME. THIS WAY YOU'RE OUT ON YOUR OWN, YOU CAN GO WHERE YOU LIKE. THAT'S WHY A GUY GETS CRANKY DOWN THERE 'CAUSE THE GUYS WILL BE WATCHING YOU JUST LIKE A HAWK. WE DON'T LIKE THAT. YOU GET ANGRY ABOUT IT TOO. YOU WOULDN'T LIKE IT EITHER. THAT'S WHY WE DON'T WANNA GO THERE NO MORE. THAT'S JUST LIKE A DARN JAIL."

Barb and Volney - Alberta

SERBIA: STATE BACKS DEINSTITUTIONALIZATION OF PEOPLE WITH INTELLECTUAL DISABILITIES

(The following is taken from a press release issued by the Open Society Mental Health Initiative December 2006)

Belgrade and Budapest — Serbia this week endorsed a groundbreaking project for the deinstitutionalization of people with intellectual disabilities. It is the first state in Central and Eastern Europe to take concrete steps to develop community-based support services on a national scale.

The deinstitutionalization initiative, called the "Community for All Initiative: Serbia", is part of a joint effort between the Open Society Mental Health Initiative (OSMHI) and the Serbian Ministry of Labor, Employment and Social Policy. Judith Klein, Director of OSMHI, and Slobodan Lalović, the Serbian Minister of Labor, signed on Wednesday a Memorandum of Understanding outlining a comprehensive plan that will be implemented by the Ministry in partnership with OSMHI and the Down Syndrome Aid Society Serbia beginning on January 1, 2007.

"This agreement marks the most significant step forward in promoting the human rights of people with intellectual disabilities in Serbian history," stated Klein.

The "Community for All Initiative: Serbia," will significantly improve the quality of life and services for persons with intellectual disabilities who are in imminent danger of admission to long stay residential institutions and for those people who currently reside in such institutions in Serbia. The project is Serbia's initial effort to foster a widespread network of family-scale support services with the goal of eliminating the need for institutional care.

Currently, a key political objective for Serbia is membership in the European Union. In order to join the E.U., a nation must be judged to follow democratic principles, respect human rights, and make progress towards meeting economic, social and political criteria. Deinstitutionalization and the development of community-based alternatives promote social inclusion and respect for the human rights of all citizens, both essential components of European Union membership.

“People with intellectual disabilities have the right to live in the community as equal citizens, and our agreement today is evidence of the Ministry’s commitment to ensuring that social inclusion of all people becomes a reality in Serbia” said Ljubomir Pejaković, Assistant to the Minister.

The need for deinstitutionalization and community-based services is also recognized at the global level. The recent United Nations Draft Convention on the Rights of Persons with Disabilities affirms the right of people with disabilities to live included in the community, to have an opportunity to choose their place of residence, and to have access to community-based services. Once finalized, the Draft Convention will be the first international legally binding convention on the rights of people with disabilities. Serbia is expected to sign and ratify the Convention and will therefore be bound by its terms. Implementing the “Community for All Initiative: Serbia” will place Serbia in a leading position in terms of compliance with the Convention.

The signing of the agreement between OSMHI and the Serbian Ministry of Labor, Employment and Social Policy demonstrates an understanding that the unjustified and inappropriate institutionalization of people with intellectual disabilities must come to an end. Serbia’s initiative is unprecedented in Central and Eastern Europe, and should serve as a model for other countries wishing to promote the human rights of all citizens.

NEW ZEALAND CLOSES LAST INSTITUTION

In November 2006, the IHC, a New Zealand disability organization, announced the closure of Kimberley Center, the last institution for people with intellectual disabilities in the country.

“This will be the first New Zealand Christmas that no one will be in an institution just because they have an intellectual disability,” said the IHC chief executive Ralph Jones. “Today, we do everything we can to ensure families are strong and are supported to care for and encourage their child with an intellectual disability in their home, within their networks and in our community.”

Since IHC was established in 1949, it has lobbied for institutions to close and for people with disabilities to live supported in the community. Self-advocates also played a great role in bringing about the closure of institutions. Their strong voice gave the New Zealand government the needed push to make the final decision.

PINS ARE STILL AVAILABLE FROM THE NATIONAL OFFICE!

Please don't forget to wear your pin and if you would like to order more call
People First of Canada, 1 204 784-7362.



One is Too Many — Stepping into Freedom

We wear these ribbons to let Canadians know that too many people are still locked in institutions.

We are horrified that Canadians keep institutions open. We are angry that new kinds of institutions are being built.

The **black ribbon** is because people in institutions are not safe. Many have died. We mourn their deaths.

The **yellow ribbon** is for liberation — we want all people in institutions to step into freedom.

All people regardless of the severity of their disabilities should live in the community with the support they need.

A campaign of People First groups across Canada

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 or Shelley Rattai at info@peoplefirstofcanada.ca for publication in our next edition (due out in May 2007).

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'Hear My Voice' — Stories told by Albertans with Developmental Disabilities who were once institutionalized — produced by the Alberta Association for Community Living

'Dialect' — Newsmagazine of the Saskatchewan Association for Community Living — Special Edition on Deinstitutionalization, Fall/Winter 2006

Conference Proceedings. Closing Institutions — Opening Communities Conference, Winnipeg, September 2006



ON DECEMBER 4, 2006 in Winnipeg, Manitoba, the PFC CACL National Joint Task Force on Deinstitutionalization joined with a group of concerned citizens to remember those people with intellectual disabilities who are still living in institutions and mourn those who did not make it out. Approximately 100 people braved a bitterly cold, winter night to participate in a candlelight vigil at the Manitoba Legislative Building. This is one of the many attempts that have been made to raise awareness around the benefits of community living since the December 2004 announcement to spend \$40 million to restructure the Manitoba Developmental Centre, an institution which currently houses approximately 370 people.

