

institution watch

PEOPLE
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OF CANADA



PERSONNES
D'ABORD
DU CANADA



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.

"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



MESSAGE FROM THE HONOURABLE MADELEINE MEILLEUR

Minister of Community and Social Services
Province of Ontario

This year marks the twentieth anniversary of the Ontario government's commitment to evolving from an institution-based to a community-based developmental services system that promotes greater inclusion and independence. It is an ambitious and extensive process, one that takes time and care. Since 1987, Ontario has closed 13 of its provincially-operated institutions for adults with a developmental disability and has helped more than 6,000 people successfully make the transition to community life.

In 2004, our government announced the closure of the last three government-operated facilities. Thanks to the dedication of community agencies across the province, we are on target to complete those closures by March 2009. Hundreds of people are moving out of facilities to good, supportive community homes where they are learning, working and making decisions for themselves. Our communities, in turn, are benefiting from their abilities and contributions.

In Ontario, institutions will no longer play a role in the lives of our fellow citizens with developmental disabilities. Our government efforts, in combination with an array of community based services and

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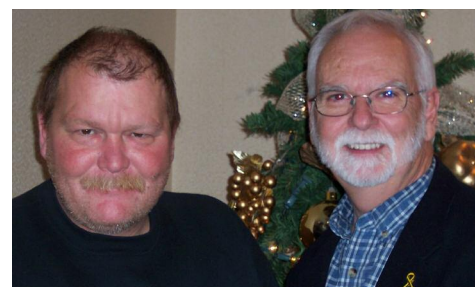
the support of families and community agencies, will ensure that persons with developmental disabilities take their rightful place in community as valued and contributing citizens. We know that community living brings enormous benefits to persons with developmental disabilities, enabling them to be part of and included in community life, and providing the opportunity to establish new friendships and participate fully in all aspects of community activities.

While we have accomplished a great deal we have much more work ahead. In May 2007 it gave me great pride to announce the McGuinty government's next step in the transformation of the developmental services sector: the introduction of a new act for developmental services. The new act would address the future needs of the transformed system and support the vision of full inclusion of all Ontarians. With your continued help and involvement, I am confident that we can build a stronger, forward-looking and sustainable developmental services system.

In closing, I would offer my support and best wishes to the Task Force in its efforts to advance the issue of deinstitutionalization across this country. I am hopeful that our efforts and successes in Ontario provide an example for other jurisdictions as they too move toward development of a comprehensive community based system — one that supports community living for all persons.

TASK FORCE MEMBERS

Richard Ruston
Norm McLeod
Shane Haddad
Dan Keaveney
Peter Park
Peter Bourne
Fred Ford
Mary Rothman
Bridget Cairns
Dale Kendel
David Katzman
Laurie Larson
Roy Skoreyko
Janet Forbes
Shelley Rattai
Faith Bodnar
Don Gallant



Richard Ruston and Norm McLeod, Task Force Co-chairs

MESSAGE FROM THE TASK FORCE

September 2007

In this edition of *Institution Watch*, the Task Force is pleased to highlight the deinstitutionalization efforts currently underway in Ontario. We are also most pleased that the Honourable Madeleine Meilleur was gracious enough to write a foreword for this edition.

In a country where today we are still witnessing provinces and territories that refuse to announce formal closure plans, and more alarmingly, in some jurisdictions, are actually seeing increased or new financial investments in institutional facilities, the efforts in Ontario are most welcomed. The commitment to the development of a completely community based residential system for persons with intellectual disabilities by Canada's largest province should be an example to all provinces and territories, and one we hope that will be soon followed by all.

The stories from Ontario are both compelling and typical. They are stories of initial concern and fear about change, and concern for the safety and well-

being of family members who will leave the only place that they have known for years. They are also stories which confirm that with appropriate planning, support from family and friends, and the necessary community supports and services the move to community is one that is to be embraced and welcomed, not feared. We hope to feature more stories from Ontario in future editions.

NEVER BE FRIGHTENED

by Natalie Miller

When her son was a small boy, Lorraine Lefaive feared for his safety. One time, Ronald ran out of the yard through an unlocked gate and played in the sewer ditch. His mom found him covered in green muck. Another time, he hit his sleeping twin brother with a tin garbage can. When he turned on the gas stove in the middle of the night, Lorraine knew Ronald, who had no sense of danger, needed help. "That's when I knew he was going to harm himself," the Windsor mother says.

At age six, Ronald, who can't speak and has an intellectual disability as a result of being born without a thyroid gland, moved to Southwestern Regional Centre, a Blenheim institution for people who have intellectual disabilities.

"It was just to give us a rest," says Lorraine. "They kept him there. They had a permanent position for him. At the time when (the twins) were born...they were really in bad shape."

Over the years, Lorraine visited Ronald there, although it was too hard on her husband, she says. "We did go and see him. The place did very well with the children. Ronald had the best of care up there." He lived there for more than 40 years.

About a month ago, Ronald, 43, and two of his co-residents at Southwestern moved into a group home in Essex. Lorraine, while initially petrified about her son's safety, says he is adjusting well and she is confident her son is in a good place.

"At first, I was very, very frightened," says Lorraine. "He doesn't know any danger."

As the government prepares to close the remaining three large institutions for people with intellectual disabilities, about 1,000 will move into community. It's part of the Province's push to offer community-based supports to people instead of institutional-based care.

The process to transition Ronald from Southwestern to the community took about three months. Lorraine says she worried herself sick but received support through the process. After attending many meetings and touring possible residences, she felt better. "Nothing's done overnight," she says. "I would like to tell (other family members) to never be frightened."

Ronald and his roommates have 24-hour support seven days a week through Community Living Essex County in their new residence. Lorraine likes the fact her son receives more individualized support now and something as simple as the smell of homemade cooking is one of his new experiences. "I couldn't get over how quiet and happy he looked."



MY SISTER BETTY

By Doris Therrin

Prior to the passing of our parents, they were informed of the proposed closing of Cedar Springs Hospital.

They were devastated but what could they do.

In 2003 our parents passed away. My brother and I just took over. We would go and visit her at the hospital and attend meetings concerning the closure. The hospital informed us that there was a gathering at Community Living Chatham, where different areas in the county each gave a presentation of what they had to offer. It was very interesting. After the meeting we were able to talk one on one with each group. We were very impressed with what they had to offer.



After much discussion between my brother and I, we decided on Community Living Wallaceburg. The appointment was made and along with DL and EVS we went to see three homes, but when we arrived at 350 Bethale Road — that was the one — the friendly people, the homey atmosphere which is what we were looking for Betty. Meanwhile Betty had a feeding tube implanted and on August 2006, Betty Jean move in. The day she moved in she was all smiles and so content. Here she was; accepted into the household by everyone from day one. Betty loves music so they bring her to church to listen to the choir, outdoor concerts, as well as the pleasant ride in the van.

Her roommate, also in a wheelchair and unable to speak loves country and western music especially Patsy Cline just like Betty. Needless to say they only play country music in the house. They are also now great friends.

Betty's primary caregiver also brings Betty shopping and like all females she really enjoys it.

It is now well understood that "the best chance for people to find the life they need and seek, rests within community rather than outside of, or at the margins of community life". (Kendrick, 2001)

Shortly after Betty arrived at the house she had a birthday. They had a cake and presents and music. This probably was the first birthday party she has ever had! I could not attend because of a previous engagement but my brother and his wife attended.

Recently we went to see Betty — here she was in her wheelchair beautifully dressed with necklace and earrings on. Her hair was nicely done. I have never seen her look so good. Her primary caregiver really does wonders with her. They had her sitting near an open door where she could see the mailman who waves at her very morning plus anyone else who walks by.

I cannot say enough about not only her primary caregiver who sees to her every need but all the other workers at the home — they care which means a lot to us. I'm sure our parents are smiling down from heaven....saying Well Done!

MY NEW HOME

By Joan Crooks

I moved into my new home in Orillia in the middle of January 2007. I had lived at Huronia Regional Centre since 1962. Over the past few months I've experienced a number of new things! I enjoy visiting with my new housemates and making new friends. I also really like a cup of Tim Horton's coffee. Now that the weather is nice I go for walks during the day to Tim Horton's at the end of the block.

Another thing that I like to do is shop. I really like the Dollarama and there is also something interesting to see at Wal-Mart or at the Mall. I recently went to a salon and had a pedicure for the first time and really enjoyed the massage chair.

On days when I don't feel like going out to do anything I love to look at magazines and sit in my new rocking chair. I recently spent a week visiting my mother at Easter, and had a wonderful time. I look forward to spending my birthday at my mom's place at the end of May.

A RIGHT TO COMMUNITY LIFE

By Natalie Miller

On her third trip from hospital back to her son's home following his Grand Mal seizure, a support worker offered the distraught mother a much-needed embrace. The memory remains poignant for Toronto senior Molly Croke, whose son, Bill, 42, has varied special needs.

"The staff at that group home are part of the extended family," says Molly, 66. "They care deeply about Bill and they care about me too. We're all part of a support system." That support system enables Bill to live in a regular house in a regular Toronto neighbourhood. It's a much different, more fulfilling experience than Bill had earlier in his life, says Molly.

Born with an intellectual disability, Bill was later diagnosed with autism. He also has epilepsy and episodes of multiple Grand Mal seizures. At age six, Molly and her husband placed Bill in Huronia Regional Centre in Orillia, an institution for people who have intellectual disabilities. Molly says in addition to Bill's medical conditions, "he was extremely hyperactive. On the average day, he was on the go at least 20 hours out of every 24 and we found it impossible to care for him at home."

They visited Bill weekly. "He never resisted going back to (Huronia)," says Molly. "That was one of the factors we used to assess if he was happy there. Being non-verbal, you have to pick up on (other hints from Bill)."

During the time Bill lived at Huronia, his parents were active members of Community Living Toronto (then called the Metro Toronto Association for the Mentally Retarded). "In the early 1980s, we learned of a project to care for the multiply handicapped in the community. This was the beginning of deinstitutionalization of developmentally handicapped individuals in Toronto."

"I was very fearful," Molly recalls. "I can totally understand what (other) parents are feeling."

When Bill moved out of Huronia, "everything was not roses," says Molly. "My biggest concern was his family physician really didn't understand a lot about developmental handicaps and made inappropriate decisions about Bill's medication." Her son wound up at the Whitby Mental Health Centre. It was a difficult time. However, the family found another physician who was better suited to meet Bill's needs. "Things have been so much better," she says. "We did have to work through some difficulties but on the whole it has been a very positive experience."

For the past 15 years Bill has lived in the same home with two other people who have special needs and is supported by staff from Community Living Toronto. "There's a lot of richness to the experiences he has," says Molly, noting her son delivers Meals on Wheels once a week and participates in activities including swimming and horseback riding.

"I'm certainly no fountain of wisdom. All I can do is share my experience. I really have no regrets at this point."

Molly recalls the bottom line that helped her come to the decision for Bill to move out of the institution. "I had to ask myself if I had the right to deny Bill of the richness he would receive in the community. The answer had to be 'no' I did not have that right."

Molly says she is willing to speak to other parents who may have questions or concerns about deinstitutionalization. Her telephone number is available through Community Living Toronto.

TRANSITION TO COMMUNITY

by Michelle Strutzenberger

Four men from Rideau Regional Centre in Smiths Falls made a "seamless" transition to a community home last year where they now live safe, comfortable and purposeful lives, according to family-members. "My god, it's just a blessing," says Lucien Alarie, parent of one of the men, Claude Alarie. Parents and family-members of the other three men are also very pleased with the new housing arrangement.

But when they first learned that Rideau would be closing its doors, none of these same family members was very positive about the change. "They were adamantly opposed to community placement," Debra Black, manager of residential services at Community Living North Grenville remembers.

Doug Graham, another parent, says his son, Richard, had been living at Rideau for 46 years. Richard, now 57, had been moved there at the age of 11 and it had been essentially all the life he had ever known. "I was quite concerned," says Graham, when he first learned that he would have to look into alternative living arrangements.

Alarie admits to the same feelings. "[Rideau] was his home," he says of his son, Claude. "He had been used to that place for 50 years."

Both parents say they had found the living quarters, staff and activities at Rideau more than adequate for their children. It was as they began searching out the community options, however, that they began to see an alternative that just might work. For Graham, the process of changing his perception began when Rideau staff mentioned to him that there were four men from the institution who would do well as house-mates. "They told me there were four men who had the same quiet disposition as my son and would make a good team," Graham remembers.

Privacy laws prohibited him from contacting the family members of these men, but staff arranged for the families to connect with Graham if they were interested in looking at a community placement together.

All three families contacted Graham and there began the transition for the four men, Claude, Richard, George, and Henryk, out of Rideau and into their — literally — brand-new home in the community. Graham says the transition was so successful due to "lot of cooperation between Rideau staff, Community Living North Grenville, and the parents."

When the families of the four met, they agreed that they wanted to look into community options together. After doing some research, they decided to look into placements in Kemptville, which is about 40 minutes from Ottawa. Graham says the smaller agency and warmth of the staff appealed to the families. "We decided they were the ones we wanted to look after our sons."

Alarie says it was meeting the board and staff at Community Living North Grenville that changed his mind. "It took away most of the worries we had," he says. "It just gave us an awful lot of confidence." The meeting with the board resulted in a decision to build a new home for the four men, as approved by the Ministry of Community and Social Services.

Construction on the house was started in the spring, 2005, in a large, quiet subdivision in Kemptville. The families were involved in the whole planning process, and their suggestions were taken into account for the new home. For zoning reasons, the house wasn't completed until the following year.

However, Debra Black, manager of residential services at Community Living North Grenville, says this worked out for the best. "To me, at the end of the day, that extra time contributed to the success," she says.

Every week throughout that year, staff from the community living association, brought the men from Rideau to the association for a variety of activities. They then took them by the house and explained that in time it would be their new home. The men had a chance to get used to their new town and new agency and to see their new home in progress.

Alarie agrees the extra time gave his son, Claude, time to familiarize himself with the new setting. "When it was time to move, he wanted to go. He knew it was his new home."

On moving day, Alarie and his wife Yolande, arrived a little after the men did. They found their son helping the movers take stuff into the house. "He had this big smile," Alarie remembers. "He looked happy." That, says Alarie, took away any remaining fears.

Today the lives of the men at the home are safe, comfortable and purposeful, according to

family members. The home is large with a fenced-in backyard, a sprinkler system and an emergency system for heating and lights. The street on which it is situated is quiet with little traffic and well-spaced homes.

Claude has a small job at a nearby long-term care home. Staff members are working at helping Richard to communicate more using alternate methods.

Alarie notes that the setting is more conducive to “family life.” At birthdays, he and his wife bring in a cake. At Christmas, they decorated a tree with the men. Both Graham and Alarie point out those staff members go above and beyond to meet individual needs and make life enjoyable. “The four families are happy and without fear now,” says Alarie, noting that all of the parents are senior citizens. “In our minds and hearts, we know our children are totally protected by that organization in Kemptville.”

FINDING A HOME IN THE COMMUNITY

By Michelle Strutzenberger

On any day at the group home where Bill lives, one may come through the front door and smell dinner cooking in the oven, hear the laundry spinning in the dryer, see the little knickknacks hanging on the walls. They are small things that many people take for granted.

But for Bill, and for Joan Tonner, his sister, they are important. They are little daily reminders that Bill has come home. For over 45 years, Bill resided at Huronia Regional Centre (HRC) in Orillia. His family moved him there in 1953, when he was five years old. “The deal was that he would be there forever,” says Joan. She and the rest of her family found a great deal of comfort and security in the institutional paradigm, knowing that Bill was well-looked-after and that it was a government-funded facility.

But as it became increasingly clear that the centre would be closing sometime down the road, the family became convinced that they needed to move Bill into the community. “We saw even then the range of services beginning to shrink there,” says Joan, adding that this was a driving factor in the family’s decision to look at other options.

But while they agreed it was important to do this, Joan, who had taken on the role of advocate for her brother, says she was definitely not keen about the decision. She was afraid for Bill. Would he receive the level of care he requires in the community?

Along with an intellectual disability, Bill has mobility limitations. He does not communicate verbally, although he can get his messages across in other ways, through sounds, facial expressions and gestures. Over the last few years, his medical needs have increased significantly and he now requires a catheter and G-tube for feeding. “Bill has always been a ‘complex-care’ guy,” says Joan. He requires 24-hour care and monitoring.

Her concerns about ‘care’ match those of families who still have family members living at HRC.

Joan says that in the experience of herself and Bill, while it has required some networking, they have managed to connect with a team of doctors, visiting nurses, physiotherapists and specialists in the community who care for all of Bill's medical needs. "It has worked for us," she says.

In an article about Bill published in *Orillia Today*, June 10, 2005, "The long journey out of HRC," Paul Doig, Ministry of Community and Social Services spokesman, pointed out that Ontario communities offer an range of options for people with intellectual disabilities, as the province has had almost 30 years of experience supporting people as they move out of institutions. "More than 370 agencies provide a wide range of services to more than 39,000 individuals with a variety of needs," said Doig. "Already living in the community [are] individuals with needs every bit as complex as residents in the three remaining provincially-operated facilities." Bill is one of those individuals.

The medical care is there for him, accessed like any other community-member would access it. The medical team does not come to Bill. He must go to his appointments. Sometimes he must wait for those appointments. But it can also be seen this way: it is another indication of the status Bill has acquired — he is a community member.

And that is huge, says Joan.

"His connection with the community now parallels what yours and mine would be," she says. "He goes to the community doctor and dentist. When we go out for walks, we go in his neighbourhood." Bill still continues to draw on specialized services as he attends a daily adult program. "But it's like us going to work or school," Joan points out. "He has a variety of environments that he interacts with. And I think that's healthy."

Needless to say, while Joan may have been reluctant about moving her brother from HRC, she and her family do not regret the move. "For us it's been a 'wow,' why didn't we do this sooner?" she says.

It was as she explored the various community-based options over a period of eight months that Joan's whole perspective was transformed. "I saw something so much better," she says. "After that, there was no looking back."

It's difficult for her to adequately express the nuances of Bill's new reality. She stresses that at HRC her brother was well cared for, the family was connected and involved with him and that staff was professional. But despite all the best efforts of everyone involved, one couldn't get away from the fact that the institution was "a big machine and a big bureaucracy."

The switch to the specialized care group home in Barrie, run by Simcoe Community Services, has just enhanced Bill's overall quality of life, she says. He is not only well cared for. He is thriving. The smaller living unit, the smaller number of co-residents, and the interaction with a defined number of staff day-to-day contributes to the home-like setting.

Bill experiences all the day-to-day comings and goings of a home such as taking trips in the van, watching dinner being prepared, hearing the laundry washing. "He also gets a lot of

personal care and attention, just by being there in the cluster function of the home,” she says. Staff-members work conscientiously to get close to Bill, to know his preferences and meet his individual needs.

Bill cannot communicate verbally, as mentioned, but through his non-verbal means, through his actions and gestures, Joan has noticed that he is evolving into a more positive and confident person. Joan has noticed times that he will stand beside a staff-member and place a hand on his/her shoulder. “This is a guy who didn’t want to be touched, who didn’t want to get close to people... That he does this now is an indication of the trust, comfort, safety that he feels.”

In the safety and peace of the home, Bill has taken to exploring things, looking at things, touching things. He even plays games now. “It’s amazing. These are unbelievable things,” says Joan. “They just didn’t use to happen.”

Joan is someone who understands the fears and frustrations of a family member of a resident at HRC. She has felt that same sense of security that families feel in depending on a government-run institution. But she points out that government dollars fund the community-based agencies which support people with intellectual disabilities. “It’s not that the government is turning its back on supporting people with disabilities,” she says. “They’ve just found a more humane, community-based, effective way to do it.”

In a letter to the Toronto Star recently, Keith Powell, executive director of Community Living Ontario noted that in addition to the individualized funding that comes with each person that leaves the institutions, the Ministry has provided \$110 million additional dollars to ensure that necessary community services and supports will exist for the people leaving these facilities. “Community Living Ontario will hold the Ministry to these commitments,” he said.

“My experience is that exploring community-based alternatives for care has yielded significant benefits for Bill’s quality of life,” says Joan. “I would encourage others to explore as well. I think they will find rich opportunities that can meet and exceed the services and quality of life provided in the institution.”

THE RIGHT CHOICE

Community Living Ontario

Joanne’s parents say they will always be grateful for the care their daughter received during the 13 years she lived at the Southwestern Regional Centre (SRC). But the Johns also know that when they ask Joanne if she would like to go back, she shakes her head.

Prior to living in SRC, Joanne spent three years at the Rideau Centre in Smiths Falls. That was a very difficult time, as her parents could only travel the very long distance to see her once every three months. They knew Joanne was unhappy because she didn’t eat.

Joanne is one of nine children born to Joe and Evelyn. Each of her siblings has achieved a

university degree and has made their parents proud. But it is Joanne's challenges that have shaped the lives of the Johns family.

In 1946, Joe and Evelyn became founding parents of the Cerebral Palsy Association which eventually expanded to become the Chatham Children's Treatment Centre and is now the Prism Centre. They also became involved when the Ontario government announced plans to close institutions that housed people with intellectual disabilities. Joe led a group that rallied support from families who wanted to keep them open. Today, while Joe still expresses concerns about whether community living is the answer for all people with intellectual disabilities, he readily admits that Joanne is happier and healthier living in the group home that she shares with four others. When they finally decided that a move back to the community was the right choice for Joanne, the Johns say that the government was very helpful. "They did a great job in making the move go smoothly," says Joe.

Joanne, who is 57 years old, may be non-verbal but she is a very emotional person, says her mother. Even something such as beautiful Christmas music can make her cry. "It's hard sometimes, not knowing exactly what she is thinking." Evelyn says her daughter is calmer since she moved to the group home. "I think she's definitely happier there being closer to us. To think — we fought it for so long."

"Deinstitutionalization is probably one of the major challenges left for society and is a severe test of just how much or how little we value human life"
(deHaan, 1981)

PROVINCIAL / TERRITORIAL UPDATES

ONTARIO

Ontario is continuing with the process of closing its final three large institutions for people who have an intellectual disability. The decision to close all institutions in Ontario was made by the government in 1987. The closure process has been done in stages through a series of multi-year initiatives to downsize or close each institution. Between the late 1980's and 2000, more than 6,000 people were supported to return to the community and 14 of 17 institutions have successfully closed. Following a 4-year delay in further closure, the government announced the last stage of the closures in September 2004. At that time there were three large institutions left in the province with approximately 1,000 residents. As of June 30, 2007 479 people remained in the three facilities. As of July 30, 2007 460 people remained. We are now a little over half-way through moving people out of the facilities and planning processes are completed or are underway for the remaining people.

During this past summer, the sector that provides community supports to people who have an intellectual disabilities in Ontario was rocked by a series of strikes stemming from workers long-standing concern about wages paid in the sector. More than 80 collective agreements came due this year in our developmental services sector and seven strikes occurred during the summer. The government has responded with an influx of new resources to the sector to

enhance wages. The seven strikes have now been settled and the labour unrest in the province has reduced considerably. There were concerns leading into this period, that the labour unrest would interfere with the ability of local Associations to plan for and welcome people home from the institutions and would therefore slow the closure process. There were in fact a few delays as some of the Associations embroiled in labour disruptions concluded that it would not be in the interest of the people returning to the community to be welcomed into a residence that might become the target of labour action. Fortunately, these delays were not widespread and we are now back on track.

Ontario is currently in a provincial election. Over the past year Community Living Ontario has expressed some concerns about the commitment of the official opposition to the closure process based on comments reported to have been made by the leader of the opposition. The Association has since met with the leader and has received assurances of his commitment to closure as long as he can be confident that everyone leaving the facilities can have their needs met in the community. We are now confident that the closure will not be disrupted by the outcome of the election on October 11.

All three institutions are scheduled to be closed by April 1, 2009 and it appears that we remain on target to achieve that goal. In fact, the institution in the southwest region of the province is well along in its process and we anticipate that facility might close before the end of 2008.

MANITOBA

Honourable Gord Macintosh, Minister of Family Services and Housing has announced that planning and financial resources are in place to enable 20 people to leave MDC during 2007-2008. This was announced prior to the Provincial Election in May and during April – September 2007, four people have returned to the community and planning is advancing for the remaining 16 people in this commitment. Six people are scheduled to leave MDC by the end of October 2007.



Val Surbey, President of Community Living – Manitoba said “We acknowledge this as progress by the Manitoba Government and clearly this is a ‘hooray’ moment for the 20 people who will leave.” “However,” Surbey continued, “We still need to address the planning options for 340 people who haven’t been selected yet.” “We will continue to pursue this issue with Government,” Surbey concluded.

On September 8, 2007 the Manitoba Government advertised for a ‘Project Director’ who will ‘be working with the Project Specialist in developing transition plans for Manitoba Development Centre (MDC) residents who are being transitioned

into community settings. With the team, the incumbent will identify and develop the least restrictive and least intrusive behavioral plan in collaboration with the community’.

In other news, the Manitoba Human Rights Commission has appointed Paula Hamilton as the Human Rights Investigator for the complaint filed against the Manitoba Government and Public Trustee of Manitoba. The complaint filed on September 28, 2006 (one year ago), was made on behalf of the 380 people with an intellectual disability who live at the Manitoba Developmental Centre in Portage La Prairie, Manitoba. The complaint comes after many attempts over the past 18 months by Community Living - Manitoba to negotiate with the Manitoba Government for the development of community living alternatives. The complaint outlines that the 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, coalitions of social justice groups and families.

Over the next several months, the HRC Investigator will proceed with an investigation of facts of the case and prepare a report for the Human Rights Commission. Currently 350 people remain at MDC.

ALBERTA

The current population in Michener Centre is 290, which is down slightly from that reported in the Spring 2007 newsletter. There are plans for another 8 to 12 people to move to the community this fiscal year. This is good news. In spite of any real political direction to close Michener, senior administration and the Central Alberta Persons with Developmental Disabilities Board are supporting people to leave the centre each year. That’s at least a partial win, but without a political decision to close the institution, any change in management or board membership could quickly reverse this positive trend.

A recent survey carried out by Michener Centre asked the people living in Michener Center if they’d like to continue living there or if they would like to live someplace else. Over 90% indicated they wanted to continue living in Michener. This type of survey has obvious shortcomings. If living within an institution is all someone knows, then of course that’s what they will choose. The people living there who were surveyed don’t know any other options. When they’ve never had the opportunity to experience what’s possible, they don’t know how to answer a survey about leaving, they can’t even dream of what could be possible.

In Alberta, there are a couple of major obstacles to moving people to the community in addition to a lack of political support. There is a lack of private guardian support and unwillingness of community agencies to accept new people. Community agencies are really struggling to find and retain staff in Alberta’s booming economy and the province’s shortage of affordable housing compounds the situation.

SASKATCHEWAN

The Deinstitutionalization Coalition of Saskatchewan was pleased to host a forum on deinstitutionalization, "Freedom, Reconciliation and Community Living for All," in Saskatoon on May 3, 2007. This national event was well attended and was a powerful, moving day. It gave us the opportunity to provide interested individuals with information about our efforts provincially as well as updates on what is happening across the country. Forum participants heard from speakers who are experienced in institutional closures across this country and heard first hand accounts of institutional living from survivors who are now successfully living full lives in the community. It also strengthened our collective commitment to moving deinstitutionalization forward.

The day prior to our forum, SACL families and the Fusion Inclusion youth group were fortunate to participate in the People First of Saskatchewan rally at the legislative buildings in Regina. This event was well attended by media and brought public attention to the issue that people with intellectual disabilities are still living in institutions in Saskatchewan. People First led the crowd with chants of "Free our People!" After the rally, members of the DCS were invited to meet with then Minister Buckley Belanger to discuss our deinstitutionalization efforts. Minister Belanger once again stated that the government of Saskatchewan fully supports community living but that they had no plans for closure of Valley View Centre in Moose Jaw at that time.

SACL met with the newly appointed Minister of Community Resources, Kevin Yates, at the legislature in July. Minister Yates reiterated that the government has no immediate plan to close Valley View Centre, but acknowledged the lack of appropriate supports in the community and committed to making changes to address this gap.

This summer, SACL met with the Leader and Deputy Leader of the official opposition, Saskatchewan Party, Brad Wall and Ken Krawetz, and discussed deinstitutionalization as one of our key priorities. We were able to raise their awareness about the issue and answer questions that they had about the implications and realities of institutional closures. Recently, the Saskatchewan Party critic for Community Resources raised concerns in the media about the critical shortage of community supports due to chronic underfunding by the government and how people in crisis are too often dumped in inappropriate places.

At the end of June the Saskatchewan government released the Disability Inclusion Policy Framework. Although this framework was meant to forge a path to address all disability issues in the province there was no mention of the existence of institutions or the people who are in them. SACL responded to the framework and pointed out this omission. A Regina-based disability group and a provincial network of disability groups wrote to Premier Lorne Calvert outlining their disappointment with the framework and the issues they felt were missed, one of which was moving forward on deinstitutionalization. In August, some DCS members attended community meetings to discuss and respond to the ideas in the framework, identifying the need to prioritize deinstitutionalization and invest in community supports.

As we head into a provincial election this fall, the DCS plans to formally ask all candidates questions about their plans for deinstitutionalization and to update the Task Force about the responses we receive.

YUKON

Yukon has no traditional large institutions designed specifically for persons with intellectual disabilities. There is however an extended care facility which houses 6 – 10 children/youth with intellectual disabilities.



NOVA SCOTIA

On August 7th, Premier Rodney MacDonald announced an investment of almost \$19M to renovate the Riverview Adult Residential Centre in Pictou County and to build three replacement 8-bed group homes. Riverview houses over 100 people. This announcement coupled with a previous commitment to build a new 24-bed institution confirms, unfortunately, that Nova Scotia intends to include institutional placement for many of its citizens for decades to come. Nova Scotia institutionalizes over 600 people.

QUEBEC

There are about 75 persons who are still live in the Riviere des Prairies psychiatric hospital although efforts are underway to find places for those people who have special needs. QACL is questioning some of the choices that have been made by a rehabilitation center such as to relocate people, with PICA problem for example, to the same place. QACL president, Jean-François Martin and vice-president, Lise Bergeron went to visit and they completely disagree with what they have seen. Jean-François Martin wrote to the Minister of Health and Social Services, Philippe Couillard to denounce the situation.

Around sixty persons are also living in the Pavillon Louise Vachon. There is very strong resistance by the parents to any efforts to move people out of the facility and as of now no deinstitutionalization activity is occurring or planned.

NEW BRUNSWICK

While New Brunswick no longer has large institutions designed specifically for persons with an intellectual disability, many people still reside in a number of residential facilities throughout the province. These facilities range in type and size and include nursing homes, for profit special care homes, and group homes run by non profit organizations. There are also a small number of people with an intellectual disability who live in two provincial psychiatric facilities.

Since April 2005, New Brunswick has been piloting a new disability support program for adults with disabilities under age 65. The intent of this pilot project was the testing of new ways to design and provide personalized and flexible disability supports that would focus on "individual development and community participation". The pilot was also designed to test ways for people with disabilities (and those close to them) to be directly involved in deciding

their goals for the future and how and by whom disability supports should be provided. This included the provision of independent planning facilitation support.

As of June 2007, an external evaluation of the pilot project was completed. Although the report has not been released publicly, it is overall very positive. Within the pilot regions, the percentage of people with various types of disabilities under age 65 receiving services in residential facilities has declined (from 32.5% to 29% in one pilot region and from 47.5% to 41.1% in another pilot region). This decline in the percentage of people accessing services in facilities has been occurring for a number of years and appears to be solidly supported by the pilot project's focus on providing personalized and flexible disability supports.

It is expected that the Government of New Brunswick will make a decision by the late fall about the roll out of a new support program for adults with disabilities.

NEWFOUNDLAND AND LABRADOR

Newfoundland and Labrador's large-scale institutions for persons with developmental disabilities have been closed since the mid-1990s. The province remains committed to ensuring that persons with developmental disabilities live in appropriate community-based settings. In early September, self-advocates with People First of Newfoundland and Labrador launched their very first provincial newsletter. The newsletter contains a number of stories from the perspectives of both self-advocates and survivors now living and thriving in the community.

BRITISH COLUMBIA

British Columbia has closed all of its large institutions, however, many individuals with developmental disabilities continue to reside in continuing care facilities and large residential settings in the community.

At this year's annual general meeting held in June, the BC Association for Community Living passed a resolution urging Community Living BC (the crown corporation responsible for community living services) to: 1) Close or reduce the size of all mini-institutions (residential facilities) by March 2009, so that no more than five people with developmental disabilities are living together; 2) Immediately develop and implement a "no admissions policy" to mini-institutions (residential facilities) where more than four people with developmental disabilities live, and 3) Ensure residential options of their choice are provided to individuals affected by this policy.

In a recent report on residential options in the province, CLBC acknowledged that closing large institutions is just part of the process of de-institutionalization. A comprehensive literature review completed for the report confirmed that people in small community homes (one to three people) fare better than those who live in large facilities. The report suggests that funding issues have made it difficult to change the configuration of many large facilities. One of the key recommendations of the report states "That CLBC establish a moratorium on admissions to homes of greater than five individuals".

In British Columbia, the challenge is clear — there are currently more than 700 individuals living in homes with five or more individuals, including several facilities with 16 to 19 individuals residing in each. CLBC has set a number of objectives for the next phase of its project, including a commitment “to engage in community development work to transform supports and create new opportunities within the current funding envelope”.

The extent of the issue of mini-institutions in BC is now better understood and the clear benefits of smaller living arrangements have been confirmed. It remains to be seen whether significant down sizing of mini-institutions will be accomplished in the near future with current funding levels. BC provides an excellent illustration that closing large institutions is just one step in the process of achieving community living and inclusion for all people.

NORTHWEST TERRITORIES

The following is an excerpt from a press release issued by the GNWT Department of Health and Social Services in March 2007. “An Adult Supported Living Facility will be built and operated in Hay River, the Minister for Health and Social Services, Floyd K. Roland, announced today....There is not sufficient residential supported living capacity in the North to meet the needs of adults with cognitive disabilities,” said Minister Roland. “With the construction of this new facility some of these clients, currently placed in southern facilities, can be brought home. Currently there are 32 adult clients residing in southern facilities. Based on a recent review of cases... approximately ten clients would be better served by a facility located in the North.”

As the Yellowknife Association for Community Living has expertise in the area of community services and supported housing, we feel we should have been consulted regarding the development of a proposed “facility” in Hay River. The facility referred to by Minister Roland follows an institutional model that by design stigmatizes, isolates and segregates. These same resources could be more appropriately directed toward the development of quality, comprehensive community-based alternatives. As other southern jurisdictions move toward closing their institutions, we hope that more of our fellow citizens will be repatriated. These citizens should be welcomed back to our communities — not to institutions!

PRINCE EDWARD ISLAND

As of today, we still have 124 individuals with intellectual disabilities housed in inappropriate settings. Our Partners for Change committee met with the previous Minister of Social Services and Seniors and anticipate meeting our newly appointed Minister, Doug Currie. In January, 2007, Partners for Change wrote a policy position paper on “Having a Home” which can be found at www.communityinclusions.ca

On October 10th, 2007 the PEI Association for Community Living in collaboration with Partners for Change will be hosting a meeting to discuss the current situation of institutions on PEI. We will be calling for a No New Admissions policy and exploring innovative approaches to supportive housing options and best practices in supporting individuals in the community.

We are very excited to be joined by members of the National Task Force and look forward to their insight on the issue and more importantly their support as PEI takes the first step towards individuals with intellectual disabilities no longer being “placed” in institutional settings.

NUNAVUT

There are no large institutions designed specifically for persons with intellectual disabilities. People who have returned to Nunavut from institutions in other provinces are now living in group homes in the community. There are still, however, many people living in institutions in the South, who have not yet been assisted to move back home.



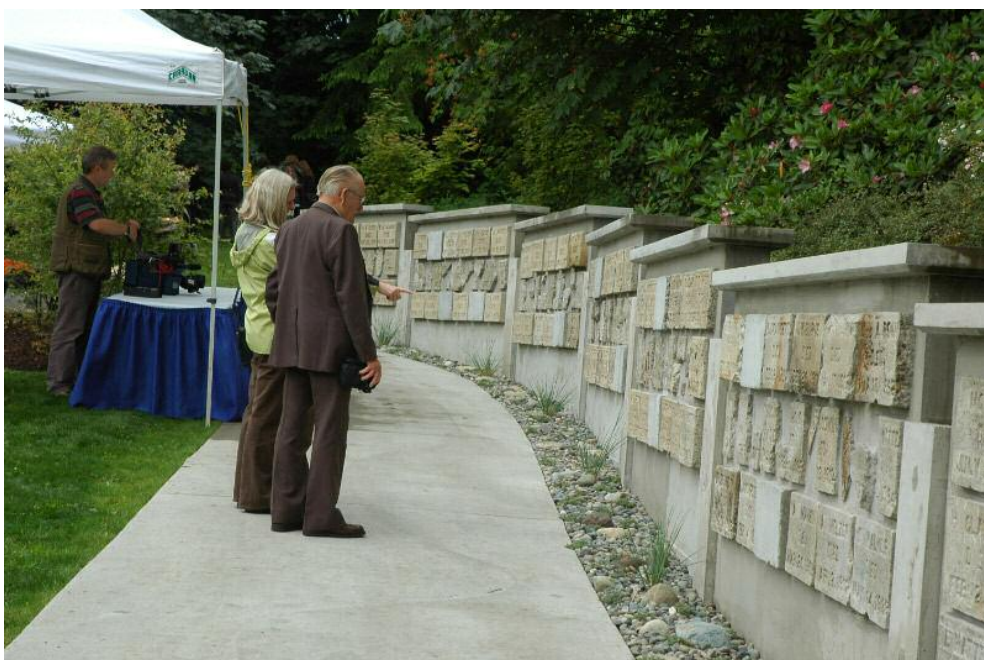
PEOPLE FIRST FREEDOM TOUR

Submitted by PFC



As part of the Free Our People Project, on August 18th, 2007, a group including five members of People First of Winnipeg, along with members of People First of Canada and the National Film Board of Canada began their travels across the Prairie Provinces in an RV. The starting point was Winnipeg. There were stops in Portage la Prairie, Regina, Saskatoon, Edmonton, Red Deer and the Closing Ceremony was held in Calgary.

The purpose of the People First Freedom Tour was to raise awareness about the benefits of living in a community versus living in an institution and to collect and share stories of those who have survived. A Walk for Freedom was held in Portage la Prairie, and Video Booths were set up along the way to help gather and record life stories. An incredibly touching candle vigil was held at the cemetery of Valley View Centre in Moose Jaw as well. As the tour travelled through the prairies, NFB filmed this great adventure. The tour ended with a video screening and gathering in Calgary, Alberta on August 29th, 2007.



WOODLANDS Dedication Ceremony

Thirty years after the Woodlands cemetery was closed and the gravestones removed, the Woodlands Memorial Garden was opened to the public this summer. Thousands of people who died at Woodlands and Essondale (now Riverview) institutions were remembered on June 22, 2007.

The BC Association for Community Living (BCACL), the BC Self Advocacy Foundation and the Ministry of Labour and Citizens' Services came together to host the official ceremony. More than 300 people attended the formal ceremony. Many stayed on afterwards to remember those who lived and died in the institutions.

The ceremony was organized to honour those buried in the cemetery, bring closure to their surviving family and friends, and finish up the eight-year long Memorial Garden Project. It was a memorable and emotional day. People came from across the province and across the nation to be present at the ceremony.

Peter Bourne, singer and former resident of Woodlands Institution, sang "We Shall Overcome". As he sang, wreath bearers carried wreaths to four compass points of the garden.

Wreaths were placed in the south pod, containing the names of many of those who had died as early as the 1920s, and in the west pod, containing

The Woodlands Memorial Garden officially opened on June 22nd of this year. As a member of the Canadian Association for Community Living /People First of Canada Joint Task Force on Deinstitutionalization, I had the privilege of attending the dedication ceremony. The garden is beautiful. A series of 21 walls were designed to hold the grave markers. Since the majority were never found, 34 black granite name panels were incorporated in free standing walls and the over 3000 names of people buried on the site are etched into the granite, ensuring that all are recognized in the memorial. One name reads simply "Unknown Lucy". At one end of the garden is a sculptural element called 'Window Too High'. This sculpture has as its inspiration stories from former residents of being unable to see out the tall windows of the institution.

Mary Rothman



the names of people who had died in the 30s and 40s. Another one was placed at the north wall and pod, containing the names of the people buried here leading up to the late 1950s. And finally, a wreath was placed to the east at the sculpture of a "Window Too High." "Window too High" was specially made to illustrate former residents' memories of being unable to look outside from the barred windows in Woodlands.

For former residents of Woodlands and other BC institutions, as well as their families, the creation of the

Woodlands Memorial Garden is an important event. The Garden is part of a healing process that has to do with telling the world about the often awful conditions in institutions for people with developmental disabilities.

Richard McDonald, a former resident of Woodlands and a member of the Woodlands Memorial Garden Steering Committee said that self advocates have been through a lot and worked hard so that people could see the past. "We want to make sure that we do not ever let this happen again. We want to make sure that families and people with disabilities can live with respect and freedom from the past," McDonald said when he spoke at the ceremony.

The Woodlands Memorial Garden, located on the site of an institutional cemetery that was dishonoured and forgotten, is the first of its kind in Canada.

In 1976, the BC government began the construction of Queens Park Hospital next to the cemetery. Woodlands officials decided that senior residents of the hospital would find it troubling to look out from their windows upon a graveyard. The cemetery was officially closed and it was called a Memorial Park. Almost all of the gravestones were removed and the names of the buried were erased from public memory.

Some of the headstones were used as "bricks" to build an outdoor barbecue patio for Woodlands staff. Others were used as part of a wall in the nearby ravine. Still others were



taken off-site to be used for a pathway in a new housing complex.

The fact that there was a cemetery was discovered during an oral history project. Later, when former residents of BC institutions were working on “From the Inside/Out” they remembered more. “From the Inside/Out” is a powerful art show about their memories of institutional life. The Woodlands Memorial Garden Project was created to bring peace to this memory.

Through the Memorial Garden Project, about 700 gravestones were found and restored. Now, the names of all of those buried in the cemetery are included in the Woodlands Memorial Garden. It remains the only trace of the more than 100 years of institutional history at this site.

The Project brought together past residents, families, local historians, students, volunteers and organizations working on institutions. The Memorial Garden Steering Committee played a key role in working on the project.

Cathy Anthony, mother of a child with a disability and member of the Steering Committee, discovered a long lost relative who lived and died at the institution. Among the 700 salvaged stones, Cathy found her great uncle Becky’s. “The chances seemed slim... yet with a hopeful heart, I asked the group to stay alert for that one stone...when one of our team found it, I knew in my heart I was meant to find him, to carry his legacy forward.”

This legacy of equality and inclusion is represented in the design of the garden. The design of the garden was carefully planned by landscape architect Eric Lees. The pods represent different generations of people who passed through the institution. The path circling the garden and connecting the various features signifies the message of inclusion. Large open space frees up the area for thinking about importance of all lives.

“After many years of working on it, we are pleased that the Memorial Garden has become a beautiful reality, and trust that this community space will reflect the importance of inclusion,” said Laney Bryenton, Executive Director, BCACL. “The Memorial not only honours those who lived in these institutions, but also serves as a solemn reminder of the negative impact of institutions on those who lived within their walls.

“Across Canada, many thousands of people with developmental disabilities continue to live in large, segregated facilities like Woodlands, without the rights that most of us take for granted. BCACL and our partners are working to address this issue, and this garden strengthens our commitment to carry forward the legacy of the individual human stories within such facilities. We hope that this will ensure that every person with a developmental disability lives a good life in the community.”





END TO “DARK CHAPTER” IN NATION’S HISTORY

LONDON, ENGLAND — The British government recently announced it is releasing £175 million (\$350 million US) to build new homes in the community for the 1,600 or so people with intellectual disabilities, known in the United Kingdom as ‘learning disabilities’, that are still housed at institutions.

***‘Our lives begin to end
the day we become
silent about things
that matter’.***

Rev. Martin Luther King, Jr.

The move will mean that the last institutions the National Health Service operates will close within the next three years. The last referrals to the institutions were made in the mid-1990s, which means that all of the residents have been housed in them for at least 10 years.

The “campuses” were supposed to have been a temporary measure for those who were not considered “ready” for the community when larger institutions were shut down. But advocates have been educating policy makers that every person can — and should — live in the community with the right level of support.

“This announcement will bring to a close one of the darkest chapters in our nation’s history,” said Ivan Lewis, the UK’s Care Services Minister. “Putting people with learning disabilities in hospitals and large-scale institutions was a scandal which disfigured our society,” he added. “People who are neither a danger to themselves or others have the right to live in the community. I am proud of the fact that by 2010 the remaining residents in NHS campuses will move into the community.”

Officials said that the needs of each resident would be evaluated, and that appropriate housing would be found to meet those needs. “Whatever they need help with — from dressing and shopping to 24-hour care — they’ll get it,” said one spokesman. “No one will be left alone.”

STATE TO DIVERT FUNDS TO COMMUNITY

FRANKFORT, KENTUCKY—“I’m happy to hear the good news.”

What made Michelle Phillips so happy was the news that the state of Kentucky has been granted permission to use federal and state Medicaid money to help an estimated 10,000 people with disabilities to live in their own homes or other community-based settings instead of nursing homes or other institutions.

“We need the services,” said Phillips, 32, who was the lead plaintiff in a 2002 class-action lawsuit that Kentucky Protection and Advocacy filed against the state. “It’s going to be just terrific for people who have been waiting and waiting for years,” the agency’s executive director, Maureen Fitzgerald, told the *Courier-Journal*.

The state had announced in January 2006 that it had settled the “Michelle P.” lawsuit, but it took until last week for the U.S. Centers for Medicare and Medicaid Services to approve the settlement agreement. Under the \$50 million dollar a year project, the state will evaluate the needs of each person currently on the waiting list for services, such as housekeeping, personal care, and employment services.

Officials hope to have the program in place by the first of this coming year.

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 January, 2008).

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The opinions and interpretations in this publication are those of the authors and do not necessarily reflect those of the Government of Canada.

ACKNOWLEDGMENTS

Articles appearing in News from around the Globe
are by Dave Reynolds, *Inclusion Daily Express*

Stories from Ontario are, with permission, from the *Coming Home: Inspiring Stories about Life in Community* as published by Community Living Ontario, May 2007.

Some of the articles have been edited or condensed for formatting purposes.

**PEOPLE
FIRST
OF CANADA**



**PERSONNES
D'ABORD
DU CANADA**

120 Maryland St., Suite 5
Winnipeg, MB R3G 1L1
T: (204) 784-7362
Toll Free for Members: (204) 784-7362
F: (204) 784-7364
E-mail: info@peoplefirstofcanada.ca
Web: www.peoplefirstofcanada.ca



**Canadian
Association for
Community Living**

Kinsmen Building, York University Campus
4700 Keele Street
Toronto, ON M3J 1P3
T: (416) 661-9611
F: (416) 661-5701
Web: www.cacl.ca
E-mail: info@cacl.ca

DECLARATION OF SUPPORT FOR **COMMUNITY LIVING**

In Canada today, many thousands of Canadians with intellectual disabilities remain trapped in large segregated institutions — inappropriately and unjustifiably segregated from society. They remain, for the most part, hidden and removed from the mainstream of society despite a collective knowledge, based on research and practice over the past 30 years, that with proper community based supports all persons with intellectual disabilities thrive in the community. They remain in these institutions as a result of inaction by governments and communities.

Therefore

...GIVEN that Canadians with intellectual disabilities are citizens and as such have equal rights to full inclusion and life in the community; are valued contributing members of our society; and are entitled, regardless of the severity of their disability, to community living;

...AFFIRMING that disability is a natural part of human diversity and that persons with intellectual disabilities, as other human beings, are entitled to basic human rights and fundamental freedoms as embedded in our Charter of Rights and Freedoms, and other national and international laws, conventions and standards;

...DEFINING an institution as any place in which people with an intellectual disability are isolated, segregated and/or congregated; any place in which people do not have, or are not allowed to exercise, control over their lives and their day to day decisions;

...RECOGNIZING that institutions deny citizenship and life in the community;

...KNOWING that institutions do not and cannot contribute to the health and well being of persons with intellectual disabilities;

...ACKNOWLEDGING the abuses that have been (and continue to be) committed against persons with intellectual disabilities within these institutions;

...CONCERNED that persons with intellectual disabilities are still being admitted to institutions rather than being supported to live dignified lives in the community;

...SADDENED by the stories told by persons who have spent years in these institutions;

...OUTRAGED by the fact that these institutions still exist despite the availability of other more appropriate community based alternatives;

...UNITED in a vision of a truly inclusive Canada, based on the values of Freedom, Choice and Equality;

WE, INDIVIDUALLY AND COLLECTIVELY, commit to working together to assist persons to return to their communities and call on all levels of government in this country to:

- Acknowledge that institutions for persons with intellectual disabilities have no place in today's society;
- Stop financing or otherwise supporting the establishment of new institutions for persons with intellectual disabilities;
- Stop all new admissions to existing institutions;
- Support the right of all people with disabilities to live in the community as equal citizens;
- Commit the necessary resources to support the development of quality, comprehensive community-based alternatives to institutional care;
- Acknowledge the wrongs that have been committed against those individuals who have been held for far too long in institutions across this country.

This Declaration of Support for Community Living can be accessed at www.institutionwatch.ca

Please visit this site and sign our declaration. The Task Force would also ask that you share this site among your friends, colleagues, and various organizations and networks.