

institution watch

PEOPLE
FIRST
OF CANADA



PERSONNES
D'ABORD
DU CANADA



50 years

Canadian
Association for
Community Living

Diversity includes.

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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



MAY 2008

MESSAGE FROM THE TASK FORCE

Shane Haddad and Norm McLeod,
Task Force Co-chairs

Why do large institutions for persons with intellectual disabilities still exist in this country? Why do they still exist despite the overwhelming evidence gathered over the past 30 years in Canada and in other countries that clearly demonstrates the capacity to support people to live successful and fulfilling lives in the community, regardless of type or extent of disabilities? Why do governments, some family members, and a significant number of the general public still hold on to and defend this model of residential support — a model that has been proven to not be in the best interests of the people who live in these facilities?

Is there really a belief that a model designed more than 50 years ago, when there were no alternate community based services available, represents the best interest of these individuals today? Has our thinking and practice not advanced in these past 50 years? Have our communities and our capacity to accept and support persons with intellectual disabilities not grown in those intervening years? Surely a decision to place a child or young adult in an institution those many years ago cannot still be considered as the ultimate, never to be changed life defining decision. Surely these individuals have a right to live in community — surely we have a responsibility to ensure that this happens.

For the members of the Task Force and the countless number of Canadians who support full community living, this is a very simple issue...persons

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 (866) 854-8915.

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with intellectual disabilities have a right to live in community and any other option is not acceptable. We believe that no one — not government, not families — should be able to take that right away. Those who do not necessarily share this view, however, put forward a position that the issue is much more complex; that the maintenance of large institutions is actually based on a genuine desire to act in the best interests of the individuals who live there. This is supported by an assumption that many of the people who still live in these institutions are too old to move, too disabled to move, or too behaviourally disturbed / medically fragile to move. That this is the only home they have ever known so why move them now.

In this and coming issues of Institution Watch we will be featuring stories from across the country that address many of these myths regarding deinstitutionalization; stories that will show these issues are not reasons to maintain institutions, merely excuses. Stories that will demonstrate that individuals with very significant challenges can leave institutions and live in community, and that the capacity does very much exist in community to accept and support these individuals. Stories that illustrate that the real questions are not whether closing institutions is the right thing to do or if we have capacity to do so, but rather do we have the moral conviction and will to do so.

MYTH #1: *"She won't survive in the community — this is the only home she knows. She will die out there".*



Carrie Anne and her three sisters"

CARRIE-ANNE RETURNS HOME

They also had to work to convince others that Carrie-Anne could and should live in the community like everyone else.

When Carrie-Anne Muir entered a psychiatric hospital on short-term admission, no one knew it would be three long years before she would return home. During the years that Carrie-Anne spent hospitalized she came very near to losing all hope of ever leaving. Because of a severe allergy to any appropriate medications, her diagnosis had no feasible treatment. A question begged to be asked: If there was no medical treatment and no behaviour modification happening for Carrie-Anne, then why was she living in a hospital? Her family and friends worked with determination to restore her spirit and hopes of returning home to her family and community.

Carrie-Anne's story is told from a number of perspectives; her parents, Mary and Danny, her sisters and a strong circle of supportive people and two people who played an essential role in helping her return to community. These two people were Charlotte, a Community Development Manager of Community Living St. Mary's and Area and Marilyn an independent facilitator/planner who was hired to facilitate Carrie-Anne's return. Below is an excerpt of the story that begins, like many others, around a kitchen table:

There is something about meeting at a kitchen table that lends itself to dreaming. This is exactly what happened at the Muir's house. Over a cup of tea, those gathered around the table purposefully ignored the file on Carrie-Anne detailing

her behaviours, mental health challenges, risks and barriers. Instead, Danny, Mary, and an Adult Protective Service Worker (APSW), and Charlotte just began to talk — about Carrie-Anne, who she was as a person, her coming home, what was possible, where would she live, and what was needed to make it happen.

This conversation was embraced by Danny and Mary, and even without a map of what lay ahead, they signed on to the idea of Carrie-Anne returning home. With the right plan, the right support, and a genuine commitment to the right to live in community - the agency was persistent in its belief that everyone could live in community — including Carrie-Anne Muir.

Charlotte and her agency had had enough experience with people moving home from institutions to know that many times, challenging behaviours often improve upon a return to community. At the same time, Charlotte was not naïve, as Carrie-Anne was a very emotionally unwell woman. When she went to visit the hospital, Carrie-Anne sat on her haunches and said very little. She was pitifully thin, and looked terribly sad. When her dad said, “Carrie-Anne, we are bringing you home,” she intoned, “Don’t believe you.” Carrie-Anne had lost hope and was severely depressed. . .

. . . Charlotte noted that as a Community Living agency, they needed help.

In particular, they needed the help of a planner/coordinator who would focus solely on the dreams, hopes, and needs of Carrie-Anne and her family. Thus, a well known facilitator/planner was seconded from her place of employment to do just that. Although, Marilyn’s services were covered by Community Living St. Marys and Area, she acted independently of them, working instead for Carrie-Anne and her family.

The word ‘planning’ can conjure up many images for people. Carrie-Anne had already experienced a great deal of ‘planning’ in her life. The planning that had been completed on Carrie-Anne’s behalf included detailed social, medical, and health histories, information on family involvement, consultations that had been made, recommendations for day activities, her psychiatric and behavioural needs, her communication skills, and information on her finances, spiritual beliefs, residential, recreational and vocational activities, her need for a ‘special’ environment, and numerous other recommendations.

When Marilyn first met Carrie-Anne, she knew that she was a very ill woman. She was obviously angry, and she was also very sad. Marilyn knew that many people had tried to find her a “placement,” when what she really needed was a home. It was her role to help Carrie-Anne and her family create that home, and to acquaint Carrie-Anne with as many of her past relationships as possible.

Marilyn related that many times, she wondered, “Oh my gosh, can we do this!?” Carrie-Anne was a severely depressed woman who had become disconnected from her family. As an experienced facilitator, Marilyn knew that the first thing she needed to do was bring people back into her life. As a facilitator, it was Marilyn’s role to ask questions: Who can we bring to be with Carrie-Anne? Who will welcome her back home? Who will support her life in community?

Establishing connections with Carrie-Anne was a feat easier said than done. For weeks, Marilyn, Mary and Danny arranged visitors to see Carrie-Anne in the hospital, and for weeks, there was little or no response. There were also people who furthered Marilyn’s doubt, like the nurse who took her aside and said, “I have met a lot of people over the years. I am not one of those people who believe that everyone should live in a hospital. But Carrie-Anne can not function. She could die. I truly believe that she can not function outside of this setting. You should stop doing what you are doing.”

However, Marilyn, Danny and Mary persisted. One of the first breakthroughs with Carrie-Anne occurred with Heather,

one of Carrie-Anne's old friends who reconnected with her in hospital. She was very direct with her friend, and the day she said, "I gotta get out of here. Let's go outside" was a day of change. From that day forward, Carrie-Anne went outside on a regular basis — something she had not done in years.

Although there were other times of doubt and struggle, Marilyn noted that "When people gather on behalf of another, amazing things begin to happen." And she was right!

Carrie-Anne had a dedicated family and support circle backing her in her return to community. However, this dedication and commitment did not go untested. They needed to be persistent and try many different ideas to help Carrie-Anne believe that they would and could support her to live independently. One idea that Carrie-Anne's mother came up with was to bring photo albums to the visits from friends and family. They were one of the first things that Carrie-Anne was interested in. At first she would only allow an occasional glance, but soon she was really looking at the pictures. Beyond any single idea, it was a commitment to Carrie-Anne's right to live in the community that kept everyone dedicated to trying new ways of doing things.

The preceding was an excerpt from the story of Carrie-Anne Muir. The rest of Carrie-Anne's story detailing her successful return to her community and family (as well as 21 other stories) will be available in the forthcoming *Kirby's Lane... A Well Travelled Path: Living, Learning and Connecting* — soon to be released by Community Living Ontario.

PROVINCIAL / TERRITORIAL UPDATES

ONTARIO

From a time when Ontario housed more than 6000 people in large government run institutions, the province is now in our final year of a closure process. As of the beginning of April 2008, there are less than 200 people living in large institutions in Ontario. This means that more than 800 people have left facilities since the fall of 2004 and two hundred people have left institutions in the past four months alone. Here is a count of the number of people in each of the remaining institutions as of April 1, 2008:

Huronian Regional Center: 53 people remain;
Southwest Regional Center: 33 people remain;
Rideau Regional Center: 113 people remain.



Southwestern Regional Centre

The government has indicated that planning processes are on track to meet the anticipated closure date of April 1st, 2009.

Community Living Ontario is moving forward with plans to celebrate the closure of the last institutions in the province and to recognize that day as an historical event. In marking the closure of institutions we will also plan an event in remembrance of those people who spent their entire lives in an institution without ever experiencing the freedoms that comes with life in the community. Our

vision for these events includes coordinated activities that can take place simultaneously throughout the province. We will keep our partners in other parts of the country advised of our celebration plans and we hope that others across Canada will join with us in celebration.

The government is moving forward with plans for a 'virtual museum' to document the history of the facilities in Ontario. Community Living Ontario continues to participate in a working group that is steering this initiative. In addition to our participation in this government initiative, we are conducting our own facilities history project to tell the stories of people who lived in the institutions and to cover elements of this history that are not likely to be included in the government initiative.

MANITOBA

Manitoba continues to make slow progress in moving people from institutions to new options in the community. The Provincial Government "Planning for Community Options" Team has assisted 11 people to leave the Manitoba Developmental Centre in 2007-2008 (target was 20) and have 20+ people in an active planning mode for 2008-2009. The population at MDC is 342 people as of April 2008. Community groups continue to call for government to announce a closure plan and to propose options and await Government decisions to proceed.



Manitoba Developmental Centre

Community Living – Manitoba via the Public Interest Law Centre brought a Human Rights complaint regarding the rights of people at the Manitoba Developmental Centre to live in the community, to the Manitoba Human Rights Commission in September 2006. This Human Rights case is moving forward and the "Report of the Investigator" of the complaint is expected in June 2008.

ALBERTA

In March of 2008 the Progressive Conservation Party was re-elected, winning an overwhelming majority of the seats in the Provincial Legislature. The appointment of the new cabinet included, the Honourable Mary Ann Jablonski, as the new Minister for the Department of Seniors and Community Development. This Department has the responsibility for providing supports to adults with intellectual disabilities. It is interesting to note that as the largest institution in Alberta is located in the Minister's riding she will undoubtedly have a special interest in supporting individuals with intellectual disabilities.

The election of any new government, particularly with the appointment of a new Minister brings challenges and opportunities. There is a need to meet and provide



Michener Centre

information on the objectives of the Task Force and to offer support to the Minister. Our goal is to work with the government to help ensure that people with intellectual disabilities are provided opportunities to live full and productive lives as equal members of our communities.

The following is the number of people living in Alberta institutions as of March 15th 2008:

Michener Centre – 281
Eric Cormack – 17
Rosecrest – 18 (children)
Youngstown – 9
Graduated Supports – (number not available)
Fort MacLeod – 18
Bow Island – 28

The number of people living in Alberta institutions continues to decrease at a very slow rate. There are over four hundred people still trapped in institutional facilities across this province, with nearly 300 people housed in the largest facility — Michener Centre. They are there not by choice, they are there because people like you and me and provincial and national advocacy organizations are not doing enough to demand their closure. We must do better!

SASKATCHEWAN



Valley View Centre

As of March 2008 there remain 255 people in Valley View Centre in Moose Jaw, Saskatchewan. This represents 7% of the total of 3,601 people who are currently on the Community Living Division's caseload (Ministry of Social Services). The cost of running VVC represents a highly disproportionate amount of the Ministry's total budget however.

In November 2007 a new government was elected. The Saskatchewan Association for Community Living has continued to speak about closure of Valley View Centre as one of our top priorities. We have informed officials that what is required in Saskatchewan right now is a complete transformation of the system of supports and services and

an investment in this chronically under funded area.

We need a focus on creating individualized, adequate and respectful supports and services so that all individuals, including the 255 residents of Valley View Centre, can have a life in the community with the supports they require. When this year's budget came down in March 2008 there was no indication that this needed investment in creating what is required to start the transition from Valley View Centre to homes in the community is planned for this year.

We will continue to speak to the government about this issue. On June 11, 2008, SACL and CACL will be hosting a Public Dialogue on Closing Institutions in Saskatoon. Members of the National Task Force on Deinstitutionalization will be in attendance and it is our hope that a meeting with government officials can

be arranged for the following day to further discuss this issue. SACL will also be having a session on deinstitutionalization at our Conference on June 13th.

YUKON

While the provision of appropriate and individualized community options for persons with intellectual disabilities remains a challenge in our Territory, 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 and youth with intellectual disabilities.



NOVA SCOTIA

The joint People First Nova Scotia / Nova Scotia Association for Community Living Deinstitutionalization Task Force held a successful forum in New Glasgow on March 19th, 2008. New Glasgow is very near the Riverview institution that has been earmarked to receive millions of government dollars in 2008 for renovations and upgrades.



Riverview

The attendance exceeded registration. In all 109 people participated. People came from all parts of the province and represented differing perspectives. There were families, people with disabilities, teachers, residential and vocational service providers, community college students and instructors, MLA's and friends. All came to hear how people can, and are, being supported to live in real homes, in real neighborhoods and in real communities. Speakers were from Ontario and Nova Scotia and included families who have seen the very positive difference in the lives of loved ones when they moved from institutions to community and from those who make it happen.

QUEBEC

The province is committed to assisting persons with intellectual disabilities to leave large institutions and does have a plan. While progress is slow, people are in fact leaving the institutions and taking their rightful place in community, with appropriate supports. The Association du Québec pour l'intégration sociale (AQIS) continues to monitor these provincial efforts.



The “deinstitutionalization” of people with intellectual disabilities comes to a conclusion in Quebec City

(first published in *Le Soleil, Québec* by Claudette Samson)

The deinstitutionalization of the individuals with intellectual disabilities living in the Robert-Giffard institution is finished. Eighty-four patients left the psychiatric hospital between 2003 and 2006, however, the last three came out in September, 2007. From now on, only people with a mental illness will be hospitalized in the facility. This is the last stage of the first wave that began in the mid 1990s and involved about 100 people, stated the Executive Director of the Centre de réadaptation en déficience intellectuelle de Québec [The Quebec City Rehabilitation Centre for People with Intellectual Disabilities] (CRDI), Sylvie Dupras.

For the President of the Board, Jean-Marie Bouchard, these developments are the result of a process launched 30 years ago by parents and professionals who believed in the rights of people with intellectual disabilities. The challenge of the deinstitutionalization is to provide the necessary specialized services in their environment, noted Ms. Dupras. The “deinstitutionalization” passed the test, she added, it enables people with intellectual disabilities to flourish. However, we should stress that it does not simply mean integrating these individuals in the community, it means helping them to become “full citizens”.

NEW BRUNSWICK



Krista Carr, NBACL Executive Director

In New Brunswick we are still anxiously awaiting an announcement from the provincial government about a new disability support program for adults under age 65. It is hoped and anticipated that this new program will improve upon the success of a recently completed three-year pilot project aimed at providing real opportunities for people to receive individualized funding and supports to live in their communities.

The government of New Brunswick has recently announced that they will build a new psychiatric facility in Northern New Brunswick to replace the aging Restigouche Hospital. The current hospital currently houses approximately 30 people with ‘significant’ multiple disabilities (including people who have an intellectual disability) who do not require tertiary psychiatric care. The government is committed to undertaking a consultation process over the next few months to determine the appropriate role and size of the new psychiatric facility. NBACL will take this opportunity to advocate strongly for properly funded and designed community support options for the people who do not require tertiary mental health services.

NEWFOUNDLAND AND LABRADOR

In April 2008 the government of Newfoundland and Labrador released Budget 2008. Building upon steps taken in previous budgets, the province again announced an additional \$12 million investment to support initiatives under the Poverty Reduction Strategy. One of the objectives of the Poverty Reduction Strategy is to reduce the poverty felt by persons with disabilities by increasing their access to employment opportunities. In addition, Budget 2008 provides \$15 million for a Long Term Care and Community Supportive Services Strategy, which will see the immediate implementation of some specific reforms, as well as the development of an action plan for future measures. These funds also include \$10.8 million to increase home support service levels.



Moreover, as follow up on the recent announcement of a Division of Disability, the Minister Responsible for Persons with Disabilities also announced the Department's intention to conduct a series of provincial public consultations in the coming months

BRITISH COLUMBIA

The Woodlands class action lawsuit brought about by former residents of Woodlands continues against the provincial government. As the struggle to get justice and compensation for the abuse suffered by former residents continues, the British Columbia Association for Community Living joins with former residents of Woodlands, their families and the community to call on government to negotiate a fair and equitable out-of-court restitution process. In February 2008, Madame Justice Satanove ruled that the Crown could not be held liable for acts committed before the Crown Proceedings Act came into force on August 1, 1974. It effectively means that all survivors who were no longer residents at Woodlands as of August 1, 1974 are denied participation in the class action and will not be entitled to any compensation should there be any successful outcome from the court case. The Woodlands survivors have launched an appeal of Satanove's order.



Laney Bryenton, Executive Director, BC ACL.

NORTHWEST TERRITORIES

The Government of the Northwest Territories is going ahead with plans to develop a "facility" in Hay River for people who have been labeled. The facility will include 3 four bedroom houses and a "day programming" building all on the same site.

People First of the NWT met with the Honourable Sandy Lee, Minister of Health and Social Services at the NWT Legislative Assembly on January 14, 2008. We explained that although we are happy that the NWT



Pierre Lafond, President, People First of NWT

Government plans to provide more services in Hay River, we are very concerned about the kind of services that are planned. We believe that cluster type housing and day services will isolate and stigmatize the people who live there. Minister Lee listened to our concerns and shared why the decision was made to develop cluster housing in Hay River. Minister Lee also sent us a letter after our meeting, which sums up what we talked about very well. The following is a part of that letter:

“The Government of the Northwest Territories and specifically the Department of Health and Social Services is very supportive of the mission of your organization and shares your values. The goal of the Hay River project is to allow NWT residents, who are currently living in the south, to come back to the north, and in

the future, to be able to offer services in the north to individuals who require the level of support that the homes in Hay River will be able to provide. The homes are being build and will be staffed for individuals who have significant needs that are unable to manage living on their own and do not have the necessary family support to remain at home.

We agree that the ideal would be to have this level of support in every community, but it is not possible at this time. We also agree that it would be ideal to have individual homes throughout the community. Unfortunately this was not financially possible in Hay River. We had the opportunity to use the land that was previously the site of a youth treatment centre and felt that the need to provide services in the NWT was so important that we should proceed with the plans for the homes, while recognizing that the clustering of the houses was not ideal.

We have and will continue to meet with residents and health and social services staff in Hay River and everything will be done so that the location of the homes and the day program does not isolate the people who will be living in them. The residents will work and recreate in Hay River and be very much citizens of this community.”

PRINCE EDWARD ISLAND



Hillsborough

While Prince Edward Island is still in the talking process with the government concerning a “no new admissions policy” we can take heart in the fact that we are indeed talking. The PEI Association for Community Living and People First PEI are committed to including an element of the deinstitutionalization issue into every event we host and to that end will introduce some of those issues at our sector forum on disability supports in June. The PEI government is doing a review of the disability support program and has held public meetings in eight communities across the province as part of that process. The concerns of Island families were heard and the fear of

institutionalization for family members was paramount. The message that there has to be appropriate housing for persons with disabilities was resounding through each public meeting.

NUNAVUT

There are no large institutions in Nunavut designed specifically for persons with intellectual disabilities. If people return to Nunavut from institutions, they are placed in group homes. There are however very limited group homes and space to accommodate these needs in Nunavut. There are still many people in the south who have not been assisted to move home and no further accommodations or housing has been discussed, approved or built to date. Until these matters are addressed there is nowhere to which to bring people home.



Group Home in Rankin Inlet, Nunavut

CALL FOR CONTRIBUTIONS

We encourage you to submit stories, Provincial/Territorial updates, pictures and/or personal perspectives on this issue. Please send all contributions directly to Don Gallant at dgallant@nl.rogers.com for publication in our next edition (due out in September, 2008).

THE FREEDOM TOUR



The Documentary

**COMING SOON
TO A THEATRE NEAR YOU**

FALL 2008



Have you signed the Declaration of Support for Community Living?

This Declaration of Support for Community Living can be accessed at
<http://www.institutionwatch.ca/>

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

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.

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



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