

institution watch

PEOPLE
FIRST
OF CANADA



PERSONNES
D'ABORD
DU CANADA



50 years

Canadian
Association for
Community Living

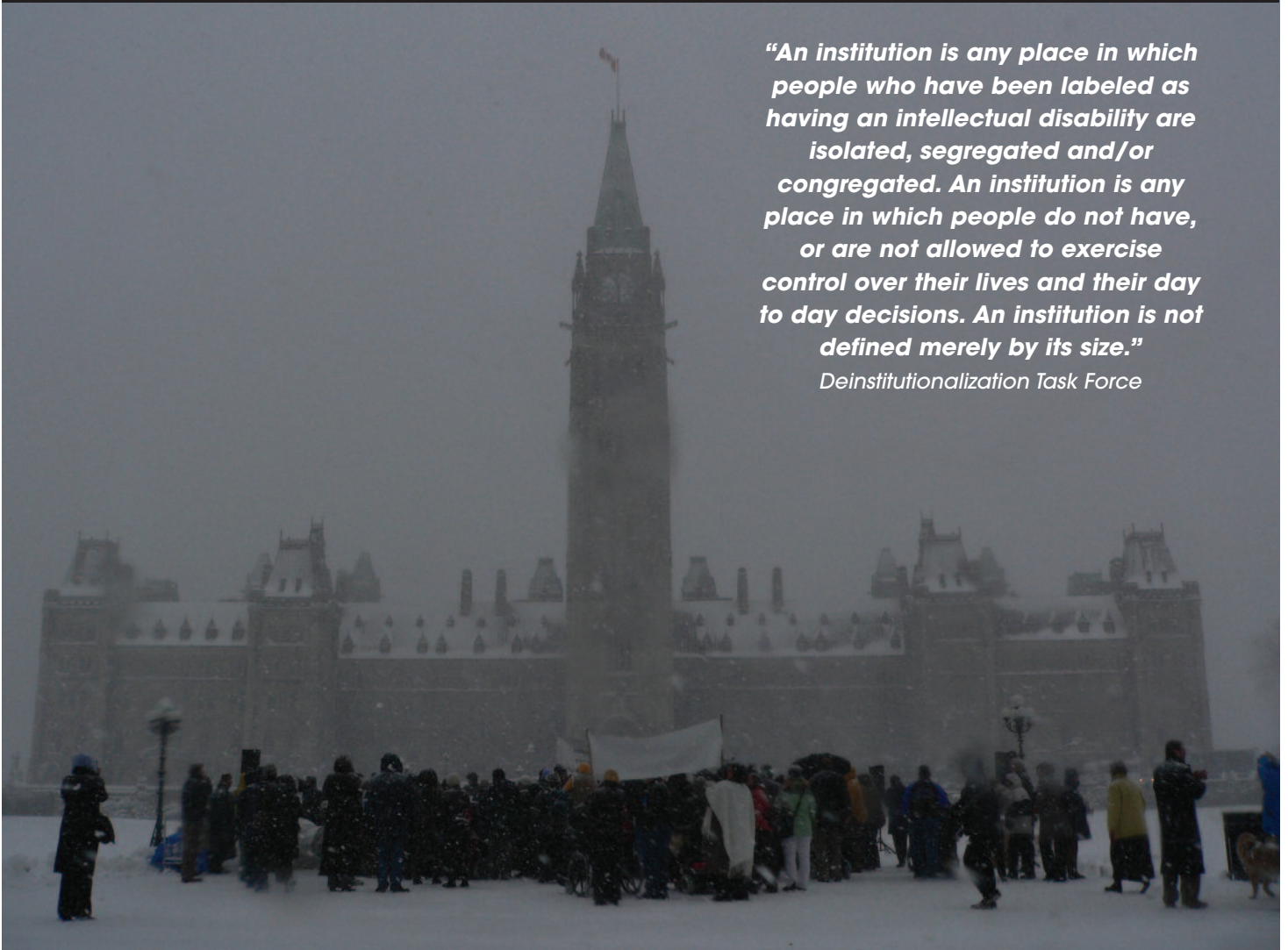
Diversity includes.

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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



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.

DECEMBER 2009

MESSAGE FROM THE TASK FORCE

Norm McLeod and Shane Haddad, Task Force Co-chairs



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To be able to live in community; in a home of our choosing, among friends and family is a fundamental right and one that many of us take for granted. Yet in 2009 this very same right is still being denied to many thousands of persons with intellectual disabilities in this country.

Even as Canada tabled the United Nations Declaration on the Rights of Persons with Disabilities signaling its intent to seek ratification, we know that there are almost 1,000 people still living in large (greater than 100 beds) institutions for persons with intellectual disabilities in Alberta, Manitoba, Saskatchewan and Nova Scotia. We know that many more thousands are inappropriately living in various long term facilities such as Nursing Homes, Seniors Residences, and/or other long term care facilities. They live in these facilities not because it is in their best interests, not because they need or want to, and not because they receive some form of specialized treatment/support not available in the community.

They continue to live in these facilities because governments across this country have decided that the creation of the needed community based supports and services is not a political priority: that the continued employment of persons working in these institutions is of greater value than the lives of the people living there. Persons with intellectual disabilities continue to live in these institutions because governments have chosen to ignore the more than 25 years of research that unequivocally demonstrates that community based supports are clearly superior to that which can be provided in an institutional environment. Persons with intellectual disabilities continue to live (and unfortunately die) in these facilities because governments, at all levels in this country, have chosen to ignore the demands of persons with intellectual disabilities and their families for the abolition of institutional responses and a call for greater availability of affordable supported housing in the community.

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities declares that "States Parties to this Convention recognize the equal rights of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community..." Canada was among the first countries to sign the Convention (March 30, 2007) and hopefully will ratify within the next several months. The Convention does not bestow any additional or special rights on persons with disabilities but rather reaffirms that they enjoy human rights on an equal basis with others. The ratification of this Convention provides an opportunity for Canada, throughout all its provinces and territories, to demonstrate real leadership, both domestic and international, in finally putting an end to the continued institutionalization of persons with intellectual disabilities.

PROVINCIAL / TERRITORIAL UPDATES

MANITOBA

Since the filing of the Human Rights Complaint in September 2006 on behalf of persons living at the Manitoba Developmental Centre (MDC), a variety of efforts to create community living options have taken place. The Joint Government / Community Transition Advisory Committee has received updates on the developing plans for persons targeted for moving into the community under an accelerated plan. Most recent information indicates that since April 2009 13 people have moved with an additional 15 people identified as being involved in an active planning process.



Demonstration at Manitoba Legislature

Since the Manitoba government's announcement to invest over \$40 million dollars in the facility, the population numbers at MDC have reduced from 380 to 296. While it is recognized that some people have moved into the community, this population decline also reflects people who have died while awaiting a move to community.

The investigation conducted by Manitoba Human Rights Commission has been completed and was recently shared with Community Living-Manitoba. A review of the content and discussions with lawyers from the Public Interest Law Centre has occurred and responses are being prepared. All parties had until November 30th to provide additional submissions. Any requests for extension of time for response by any party will further delay matters. Once responses are received from all parties, the MHRC will provide direction as to next steps.

"The developmental services system put me in a place that I find hard to pronounce. It is called a domiciliary hostel. I just called it the residence. I had a tiny room on a metal bed in a basement along with another 30 people in the building."

NORTHWEST TERRITORIES

As reported in previous editions of *Institution Watch*, the Government of the Northwest Territories established a cluster housing model to provide supported living services to those with an intellectual or developmental disability in the Northwest Territories. People First of the NWT and the Yellowknife Association for Community Living expressed concerns, to the Minister responsible, about the service model chosen and the fact that a day programming building would be located in close proximity.

The Minister's response indicated her understanding of the issues and acknowledged that cluster housing was not ideal (see *Institution Watch*/Spring 2008). Despite our concerns, the Yellowknife Association for Community Living will work with the Department of Health and Social Services to ensure that the new facility reflects our values. In support of this, Association staff sit on the selection committee which assesses and approves applications from potential residents. We also liaise regularly with the Department's Supported Living Planner.

NEWFOUNDLAND AND LABRADOR



Newfoundland and Labrador was successful in closing its institutions for persons with intellectual disabilities in the mid 1980s. However, many people with intellectual disabilities continue to live in other institutional settings such as long term care homes, nursing homes, and seniors residences. While no accurate data is available as to the exact number of people inappropriately placed in these facilities, NLACL recently contacted a small sample of long term care facilities in the province. Of the 21 facilities contacted, only eight provided an answer to our inquiry. Of these, five facilities stated that they currently have at least one (in some cases two or more) individual with an intellectual disability in their care.

NLACL will be conducting further inquiries into this area with a view to gaining a more accurate estimate of the number of people who are inappropriately housed in these facilities.

There is clearly a real need to address the housing situation for people with intellectual disabilities in this province. A lack of affordable housing and inadequate access to needed supports are the current major barriers faced by individuals with intellectual disabilities when attempting to establish homes within their communities.

We have a responsibility to ourselves, and to our fellow citizens to say no one, no one, should live in an institution

Although Newfoundland and Labrador Housing will assist persons with intellectual disabilities to obtain independent and affordable living, all too often they remain for months on a waitlist. It is also noted that the affordable housing units provided to individuals with intellectual disabilities, as well as those with other social barriers, have a tendency to be congregated in one area. This is a concern as it does not allow for true integration into the community at large.

Recently, changes to government policy have been made to assist individuals with intellectual disabilities to break down barriers to inclusive living as part of our government's Poverty Reduction Strategy. Many of these changes had been long sought by NLACL, and include increased Board and Lodging payments, and enhanced funding for physical accessibility. Home support services, an essential support needed by many persons with intellectual disabilities, is unfortunately still capped and this makes it very problematic (if not impossible) for many persons to maintain an independent home in the community. If we are to remain true to our stated policy of community living and provide an equal opportunity for all persons to live in community then clearly reform of current services is needed.

NUNAVUT



Group Home in Rankin Inlet, Nunavut

There are currently no large institutions designed specifically for persons with intellectual disabilities in the Territory of Nunavut. People who have returned from Nunavut from institutions are for the most part living in group homes. There are still, however, many people living in institutions in the South, who have not yet been assisted to move back home. We are not aware of any formal plan to assist in their repatriation.

NOVA SCOTIA

The Nova Scotia government continues to open new beds in existing institutions for people with disabilities. Although the exact number of institutional placements is not known, we are assured that over 700 Nova Scotians with disabilities are housed in institutions. Nova Scotia has a population of less than one million people. These institutions are known as Regional Rehabilitation Centres or Adult Residential Centres. In addition, large group homes and 'community residences' also exist.

In September of 2009 Canadian Press reported that there had been 49 confirmed cases of abuse of residents in facilities for adults with disabilities over a 22 month period. Nineteen of these cases occurred in one institution that houses approximately 100 people. The Department of Community Services is conducting an internal review of these cases which include physical abuse and neglect by staff as defined by the Protection of Persons in Care Act.

The Nova Scotia People First and NSACL Joint Task Force on Deinstitutionalization continues to work with government and other like minded organizations on these issues.



Riverview

The following are descriptions of mistreatment as contained in reports stemming from 49 cases of abuse at Nova Scotia residences that were reported between October 2007 and July of this year.

- A worker is reported to have sprayed water on a female resident's head "to the point where she was gasping for air."***
- When a resident refused to drink water after taking pills, the worker pulled down the top of the resident's pants and poured water on him. The worker then held the resident's arms across his chest with one hand and put a knee on his lap, then put the cup to his lips "where the water ran down the front of his shirt."***
- A residential rehabilitation worker grabbed a (female) resident by the leg above her ankle and pulled her down the hallway to another unit ... Another ... worker, present at the time, did not stop the first residential rehabilitation worker.***

YUKON

The City of Whitehorse is still conducting an Official Community Plan (OCP) Review. One of our concerns relates to the overly restrictive zoning by-laws and their implications for people with intellectual disabilities to live in "staffed" homes in residential areas. According to the City's interpretation of the by-law, they do not permit small group homes staffed by non-family members in residential areas. This creates a barrier to community inclusion for adults with disabilities and other groups of people who require residential supports. Other than the long-standing homes, which have been grandfathered in, any new group home in a residential area would have to apply to be rezoned for this usage. While we anticipate a lengthy process, we are hopeful of working with the City to improve the current system and thereby positively affecting the ability of people with intellectual disabilities to live (with support, as needed) in community.



ONTARIO



Ontario Vigil, March 2009

After the final three institutions were closed in March of this year Community Living Ontario's Deinstitutionalization Working Group held a retreat to look at the challenges that lie ahead. There is still much unfinished business in Ontario related to institutionalization including: ensuring that people living in other forms of institutions (long term care facilities etc.) have the opportunity for real community life; ensuring that community programs and supports are not re-creating institutional models in community; promoting a comprehensive history of the institutionalization movement;

investigating the whole area of reconciliation and healing; assisting with the national agenda of community living; and maintaining a watch-dog role to ensure that no forms of institutions are again created.

As part of the ongoing process related to the recent closures of the last of the provincial institutions in Ontario, the government of Ontario has commissioned a review called "The Facilities Initiative Study – The Transfer of Former Residents to Community Living". The study, being conducted by researchers at Brock and Lakehead Universities will focus on: changes in health and well being of the former residents; how they have accessed supports and services as a result of individualized planning; impact on their personal networks (family and friends); and factors that have contributed to the person's health and well being.

The researchers will be focusing on 200 of the people who moved to the community as a result of the final institutional closures in Ontario. Results of this research will be shared as available.

"I had a roof over my head and I had three meals a day provided for me. But it did not cure my loneliness and only increased my disconnection from the community. My life was about eating and sleeping, sleeping and eating."

It is further noted that at its Annual Meeting in June the members of Community Living Ontario unanimously adopted the following Call to Action to move its work forward in the post institution era in the province.

Creating and maintaining large government-operated institutions was one of the most harmful things we have done as a society. Gradually the harm we were causing people was recognized. We had to stop. On March 31, 2009, the doors of the remaining three large government institutions for people who have an intellectual disability closed forever in Ontario.

This splendid moment marked the end of decades of struggle for people who have an intellectual disability, their families and friends, other citizens, community organizations, and government working together to do the right thing.

In the heart beat of time that we paused to celebrate the closures we realized that the struggle is far from over. Among the many challenges facing us in the future, three in particular call us to action:

“I don’t think members of the public or their elected officials realize how common it is for people like me to end up in a hole in the wall, out of site, forgotten.”

1. We fully recognize that there are similar forms of residential institutions in Ontario and we must prevent people from being institutionalized in them simply because they have an intellectual disability. We must also work to enable those who live in such institutions to return to community.
2. We will continue to eliminate harmful and controlling approaches from the choices offered to people who have an intellectual disability and will ensure that institutional practices are not transferred to community settings.
3. We will continue our work to open communities as wide as possible so that people who have an intellectual disability are respected and welcomed citizens. We will confirm the fact that we and our communities are not fully human without the diversity that comes with the inclusion of people who have an intellectual disability.

We know that it is within our power to ensure that people who have an intellectual disability can be safe in the community without requiring them to give up their rights and liberties.

We will act together as communities to support each other. We will encourage those services and supports that promote inclusion, and work to eliminate any that exclude people from community. We will call upon our values, beliefs and principles that help us meet these challenges, not those parts of our culture and habits that keep people who have an intellectual disability apart from us and the lives to which we are all entitled.

We are used to challenges. We are also not always sure about how to meet them. We will struggle together, in community after community, to develop ways that work, not only in Ontario, but throughout Canada.

Approved June 5, 2009 – AGM – Community Living Ontario

QUEBEC

The situation in Quebec remains much the same as in previous updates. According to the latest available data, there are approximately 350 people with intellectual disabilities still living in institutions in the province of Quebec. While progress is slow, the province is committed to assisting persons in leaving these institutions. The Association du Québec pour l’intégration sociale (AQIS) continues to monitor these provincial efforts to ensure that as people leave they have access to appropriate supports in the community.



BRITISH COLUMBIA



Centre Block, former Woodlands Institution

On a recent visit to Campbell River and in meeting with the Campbell River and District Association for Community Living (CRADACL), representatives of the BC Association for Community Living had the opportunity to experience first hand the changes that have been incorporated into the plans for the new project that was announced last April. While it was initially announced that this new project would include '24 residential units' for people with intellectual disabilities, the most recent plans are for three one-story townhouse buildings with eight, one- and two-bedroom suites in each. The local ACL will support three to four people with intellectual disabilities in one of the eight-unit townhouses and will rebuild an existing four-bed group home on the site. The Campbell River and North Island Transition Society will operate the other two buildings, providing services to women and children dealing with issues of abuse and violence. In addition, the site will feature a community kitchen and gathering space that will be open to the larger community as a place for gathering and activities.

Representatives from the CRADACL welcomed the BCACL representatives, indicating that the project is a work in progress and their goal is to be part of meeting the housing needs of their entire community.

As funds shrink and waitlists grow, concern is also growing that there will be a call for larger and more institutional residential developments and segregated education. It seems that we are at risk of forgetting where we have come from and are now reacting to funding pressures. It has never been more important to ensure that the legacy of institutions and segregation is not forgotten and the rights of people with intellectual disabilities to live fully included lives in their communities is safeguarded as we move through difficult times.

There are lots of people out there who are not so lucky and spend their entire lives excluded from the rest of their community.

The City of New Westminster is proceeding with a new round of community consultations regarding the fate of the Centre Block ruins on the site of Woodlands Institution which closed in 1996. The Centre Block was almost completely destroyed by fire in 2008. Members of City Council and the Mayor have stated publicly that the remaining structure will not be re-purposed for 'retail/commercial'. This comes after several rounds of

meetings with council members and city staff to ensure that the decision regarding the Centre Block is informed by the experiences of former residents and that accurate information regarding the documented abuse that occurred at Woodlands was provided to all involved.

PRINCE EDWARD ISLAND

PEIACL is very pleased that as a result of the Disability Support Review process the Disability Action Committee, comprised of community advocates, government staff and people with disabilities, has been formed. This group will serve as an advisory body for legislation, policy, programs and services for persons with disabilities. The Review process clearly told government that an evaluation of current programming and service delivery was necessary and that efforts must be undertaken to move from an

institution centered model to one that is person centered. The recommendations coming from the Disability Support Review process will be the guiding force for this Disability Action Committee. Copies of the report including a full list of recommendations are available through the Department of Social Services and Seniors by calling 1-866-594-3777 or on the government web site at www.gov.pe.ca/disability/



Hillsborough

While there is still considerable work to be done it is heartening to know that the provincial government is working with disability groups to ensure the development of more inclusive community options. Of particular significance is the recent Speech from the Throne, in which the PEI government indicated that 'action will be taken over the coming year to ensure that Prince Edward Island is in compliance with the United Nations Convention on the Rights of Persons with Disabilities'. The Throne Speech further indicated that 'over the coming year, my Government will continue to develop existing programs and make them work together more effectively – and will explore and identify new measures to increase well-being and inclusion for all Islanders'.

SASKATCHEWAN

The Government of Saskatchewan has had a no-new admittance policy in place for Valley View Centre (VVC) in Moose Jaw since October of 2002. There have been no 'official' placements made for some time and the number of residents has decreased.

Currently there are 236 people residing in VVC. While it is acknowledged that the closure of VVC is inevitable if the decrease in residents continues, the Government of Saskatchewan has not committed to a planned closure process or to the necessary investment to create the required services and supports in the community to ensure that all residents can access a life in the community.



Signing ceremony.

In May 2009, after much discussion, SACL, People First Saskatchewan and the Valley View Centre Family Group reached an agreement to work together to call for a closure plan that is respectful, successful and transparent. A letter, signed by representatives from each of these three groups, was sent to the Minister of Social Services which states that "Collectively, we agree and respectfully request that the Government of Saskatchewan make a commitment to the planned closure of Valley View Centre and the development of personal transition plans to support each resident. The personal transition plans must and would include input from family members, other supporters and advocates in the community."

A meeting was requested to discuss the government's future plans for VVC. On November 6, 2009 the first meeting between Ministry officials and SACL, PFS and the VVCFG was held. These officials stated that there is currently no concrete plan in place by the Provincial Government to close VVC in Moose Jaw. They have however, agreed to continue the dialogue and a second meeting has been scheduled for January 2010. We remain hopeful that the Government will provide the necessary investment so that planning can begin with individuals and their families to create homes with the needed supports in the community.

ALBERTA



Michener Centre

There have been no announcements regarding the possible closure of institutions in Alberta. Michener Centre, the largest institution in Alberta, currently houses 253 people. Michener Centre operates another facility in Youngstown for 16 people with intellectual disabilities. There have been no new admissions to Michener Centre during the last year. The number of people living at Michener continues to decrease not because of people moving to the community but due to deaths.

Alberta has the potential to move forward in closing its institutions. The Minister of Seniors and Community Development the Honourable Mary Anne Jablonski

understands the merits of people with developmental disabilities being included in their communities. She also appears open to discussions on best practice and implementing models of supports that empower, respect and enhance the diversity of our communities. At this point whether this leads ultimately to a rethinking of the current status of Michener Centre is unclear.

The Self Advocacy Federation in Edmonton, a group of about 30 people with intellectual disabilities, previewed the People First of Canada documentary film *The Freedom Tour* and will be hosting a Red Carpet Film Night in January. The film will be shown at the Woodcroft Public Library and will be open to the general public. This is an excellent opportunity to provide the general public with the message from people with intellectual disabilities about the horrors they experienced living in an institution.

The People First movement in Alberta is also being re-established and will have an important voice in shaping how supports should be provided to people with intellectual disabilities in the future.

NEW BRUNSWICK

The government of New Brunswick continues to roll out the new Disability Support Program with two regions being added before March 31, 2010 and the remainder of the regions to be added by March 2011. This new program is providing individualized and flexible disability supports to adults (ages 19 to 64) so as to facilitate their personal development and their participation within the community. In addition to individualized funding, the program is promoting personal involvement and control over planning for supports by using person centred approaches to developing disability support plans and by providing access to independent planning facilitation (through NBACL).

The provincial government has also given its approval for the replacement of the Restigouche Hospital Centre with a new smaller psychiatric facility in northern New Brunswick. This will mean that over 30 individuals with an intellectual disability will leave the current facility over the next two years. A consultant is being hired to oversee the process of planning for the release of these individuals and NBACL will be involved in the planning process.

NBACL has also developed a proposal for the development of “inter-professional teams” to be created to provide better support for people with an intellectual disability who have a concurrent mental illness. One

of the goals of this proposal is the development of provincial expertise to provide adequate support for people with a dual diagnosis (and their families) so that they can remain in their chosen community.

NBACL is also working on a proposal to develop “supported living” opportunities for adults with an intellectual disability so that they can live in their own homes. This is aimed at providing the community resources required to support people to live in their own homes – including the ability to assist people with planning, implementing and monitoring supported living arrangements.

Lastly, NBACL has also had discussions with the Minister of Social Development and department representatives about the need to develop alternatives to nursing home care for younger adults with intellectual and other disabilities who require more intensive supports. This has been in the context of supporting individuals who are at risk of nursing home “placements” without the appropriate supports to remain in the community. This issue will require our on-going attention in the coming months and years.

PEOPLE FIRST OF CANADA

Around the country and around the world, People First of Canada moves forward and expands its work on the issue of deinstitutionalization. *The Freedom Tour* continues to open minds and change hearts and remains our best and most used tool in the toolbox this year. There were premieres held in NL, Yukon, and in Ontario where there were coordinated multi-screening events in several communities. The screenings help bring the issue of institutions to the forefront and educate people on what can be done.

People First of Canada was also involved in other events and activities – there was a vigil held in Ontario to raise awareness of the people who have died while in institutions, and public dialogues around institutions were held in PEI, Ontario, and Manitoba. There were also panel discussions in both Manitoba and the Yukon around deinstitutionalization.

On December 3rd, 2009, People First of Canada and many of its chapters around the country were involved in events to mark the International Day of Persons with Disabilities. A vigil was held in Manitoba, and several screenings of *The Freedom Tour* were held in the Yukon, along with a panel discussion around deinstitutionalization.



Vigil at Manitoba Legislature

On December 3rd, PFC also conducted the ‘Postcards with a Purpose’ campaign which involved every provincial and territorial chapter of PFC. The campaign saw over 2,500 postcards go to the Canadian government and provincial and territorial governments asking them to support ratification of the Convention.

Being involved and providing input into work around the UN Convention on the Rights of Persons with Disabilities has been a good part of the work PFC has been involved with in recent months. This Convention protects and promotes the right to live in the community and is important to the deinstitutionalization movement. Once it is ratified, another powerful tool will be available to everyone working towards full inclusion of people with intellectual disabilities.

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 March 2010).

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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