INSTITUTION WATCH

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

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

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MESSAGE FROM THE TASK FORCE

This joint PFC–CACL Task Force on Deinstitutionalization was formed nearly four years ago, with an intent of increasing the awareness of Canadians regarding the plight of persons with intellectual disabilities still trapped in institutions, and advancing pan-Canadian efforts regarding deinstitutionalization. We believe in some small way we have been successful with respect to our public awareness efforts and in re-establishing deinstitutionalization as a priority issue of both People First of Canada and the Canadian Association for Community Living. Our second object, however, remains frustratingly unattained.

> **"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*

During these past four years we have encountered a federal government unwilling to provide real and substantive leadership at either a policy or fiscal level, noting that institutions fall within provincial/territorial jurisdiction. At the provincial/territorial level we have heard the rhetoric of deinstitutionalization as government policy, yet all the while witnessing continued admissions of persons with intellectual disabilities to these facilities, an absence of plans to assist people to leave these facilities, and in several provinces, government announcements of new fiscal investments in institutional facilities. The Task Force does wish however to recognize Ontario as the singular exception to this


Norm McLeod and Shane Hadded, Task Force Co-chairs

trend, in that the Ontario provincial government has announced closure dates for its remaining three large institutions.

Throughout this country individuals and families have told us of their fears — a fear of a future life within an institution, a nursing home, a long term care facility or some other congregate care facility. We have heard stories told by individuals who have endured years of institutionalization who now speak with remarkable clarity and courage on behalf of themselves and others who still remain hidden from society. They openly question why our society and our governments so undervalue and disrespect persons with intellectual disabilities that they would assign them a lifetime of institutional living. Why indeed?

> **THE FORCED CONSIGNMENT OF PEOPLE WITH INTELLECTUAL DISABILITIES TO INSTITUTIONS FUNDAMENTALLY VIOLATES THEIR INDIVIDUAL LIBERTIES. THEY HAVEN'T COMMITTED A CRIME, YET THEY ARE CONFINED. THAT IS NOT AT ALL IN ACCORD WITH THE BASIC VALUES OF SOCIETY AND OUR CHARTER OF RIGHTS AND FREEDOMS. PEOPLE RECOGNIZE COMMUNITY LIVING AS A HUMAN RIGHTS ISSUE AND CANADA HAS BEEN REGARDED AS A LEADER IN THIS AREA. BUT THERE'S A HUGE GAP BETWEEN RHETORIC AND THE REALITY. THIS COUNTRY IS STILL NOT MEETING ITS COMMITMENT TO PEOPLE WITH INTELLECTUAL DISABILITIES.**
> *Michael Bach, EVP - CACL*

> **I GOT OUT OF VALLEY VIEW SO LONG AGO NOW. THAT'S PROBABLY THE BIGGEST SUCCESS IN MY LIFE, TO GET OUT OF THERE.**
> *Neil – Saskatchewan*

INSTITUTIONS STILL REMAIN

The vast majority of persons with intellectual disabilities live in community — as our friends, family, colleagues, neighbours, co-workers, and fellow citizens — that is a fact. Equally true however is the fact that many thousands of people remain trapped in institutions — confined to facilities and lifestyles not of their choosing.

While not intended to be an exhaustive commentary, the following provides a quick summary of the numbers of people with intellectual disabilities living in the larger institutions that remain in operation across this country: Where known, annual budgets are also provided. While it has proven to be difficult to obtain complete, up to date information regarding these institutions, in future editions of Institution Watch we hope to publish other relevant data such as numbers of new admissions, average length of stay, number of discharges, etc.

ALBERTA — 6 large institutions — 527 people
Michener Centre — 345 people — $42,600,000
Scenic Bow Legion — 71 people — $5,360,000
Eric Cormack — 34 people — $4,460,000
Pallister — 30 people — $2,700,000

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Youngstown — 25 people — $1,730,000
Chinook — 22 people — $2,280,000

SASKATCHEWAN – 3 large institutions – 413 people
Valley View — 313 people — $20,300,000
Parkridge — 30 people
Elm Wood Lodge — 50 people

MANITOBA — 2 large institutions — 596 people
Manitoba Developmental Centre — 380 people — $31,000,000
St. Amant Center — 216 people (including children) —- $22,200,000


Valley View

ONTARIO — 3 large institutions — 1079 people
Rideau Regional Centre — 445 people — $32,900,000
Huronia Regional Center — 352 people — $31,900,000
Southwest Regional Center — 282 people — $22,700,000

QUEBEC — 3 large institutions — 525 people
Data collected from Quebec indicate there are three large institutions — Riviere de Prairie, Hyppolite LaFontaine, and Robert Gifford Center. There are approximately 525 institutional placements in the province and these are distributed across the province (in these and other facilities) as follows : Laval (62), Quebec City (100), Montreal (185), Ouatouais (15), Abitibi (41) and Laurentides (122)

NOVA SCOTIA — 12 large institutions — 696 people
Braemore Regional Rehabilitation Centre — 54 people
Braemore Adult Residential Centre — 70 people
Quest Residential Support Centre — 11 people
Pictou County Adult Residential Centre — 106 people
Sunset Adult Residential Centre — 115 people
Annapolis County Adult Residential Centre — 33 people
Bayside Adult Residential Centre - 20 people
Harbourside Adult Residential Centre — 32 people
Kings Regional Rehabilitation Centre — 84 people
Kings Adult Residential Centre — 70 people
LeHavre Manor Adult Residential Centre — 66 people


Kings Regional Rehabilitation Centre

PRINCE EDWARD ISLAND — 2 large institutions — 37 people
Hillsborough Hospital — 24 people
Sherwood Home — 13 people

The above numbers do not represent the full extent of institutional placements on behalf of persons with intellectual disabilities in this country, but merely the larger facilities and those most commonly used exclusively for persons with intellectual disabilities. We also know that there are many thousands more people, in all provinces and territories, who are living in other environments inappropriately suited to their needs such acute care hospitals, long term care facilities, personal care homes and seniors' facilities.

Incomplete thought the data is, one can however still begin to understand the extent of public dollars that are directed toward the maintenance of institutional placements. Based on known budgets for the facilities in our list, there is an annual expenditure of nearly a quarter **billion** dollars, for approximately 3,850 people. Based on the number of people living in facilities for which budgets are known, the annual expenditure **per person** is approximately $87,000. Surely this money can be better spent through investment in supports and services that afford persons with intellectual disabilities a real and meaningful life in community.

PRIORITY ISSUE

During the past year and a half CACL has engaged in a strategic planning process guided by the efforts of its Strategic Planning Task Force. This process resulted in the drafting of a 10-point, 10-year plan entitled **"From Values to Action."** This document provides the basic framework for a 10 Year Planning Process and consolidates CACL beliefs and values, with a vision, goals and benchmarks to guide efforts over the next 10 years. One of the priority goals identified by CACL during this process was deinstitutionalization, with associated benchmarks as noted below:

Close Institutions — Assure a Home In The Community

Benchmarks:

- By 2007 no admissions to large institutions
- By 2010 close all large institutions for people with intellectual disabilities
- By 2013 reduce by 50% those in inappropriate settings — like nursing homes
- By 2015 all supported living based on choice, self-determination, individualized funding
- By 2015 People with intellectual disabilities have access to the full range of housing options in the community

Deinstitutionalization means having:

- The right to choose where one will live, and with whom;
- Services/programs that are directed and controlled by the person and that are respectful of the right to make choices, and take risks;
- The right to individualized living arrangements and control over the required individualized funding;
- The necessary disability related supports needed to fully participate in the community;
- Support, as necessary, from friends/family/advocates to assist in decision making (supported decision making);
- Services that meet all identified needs and are of high quality, portable and accessible.

ONTARIO UPDATE

Submitted by Gordon Markham

During 2005–2006, even though there were some complications to the placement process as a result of the legal process initiated by family members who did not want their son/daughter, brother/sister moved out of the Facilities, 113 of the 998 people living in the three institutions did actually move. Additionally, the following occurred during that year:

- 214 residential spaces were created in community
- 1 Long-Term Care placement was made for an individual who met all of the admission criteria for a Nursing Home
- The Ministry reports that they held an average of 30 meetings with each family for the purposes of planning
- 315 residents of the 3 institutions were involved in some stage of the "planning cycle"
- The Ministry also reported that the average length of planning was longer than they had expected, and the levels of support needed by the people moving out of the institutions had initially been underestimated by the Ministry

At this point, the community of choice for each of the 885 people still in the institutions has been identified, and all of them will be placed in community-based settings by March 31, 2009 at which time the last of the institutions in Ontario for people who have a developmental disability will close.

MANITOBA UPDATE

Submitted by Dale Kendell Executive Director

In December 2004, the Government of Manitoba made a surprise announcement that they were committing 40 million dollars to redevelop the Manitoba Developmental Centre in Portage la Prairie. This announcement essentially meant that 350 Manitoba citizens with an intellectual disability will be living in an institutional setting for the foreseeable future, if not for the duration of their lives. Since that time, those individuals and organizations who believe that all citizens with an intellectual disability should live within communities, have come together under the leadership of the Association for Community Living — Manitoba and have pursued the following activities:

- Studied and listened to the experiences of other provinces and states who have turned completely away from institutions and now offer a range of community options.
- Examined the scientific research that has evaluated living conditions, happiness, safety, cost and like factors for individuals in those provinces and states who left institutions and now live within community settings.
- Produced and submitted to Government a "Community-Sponsored Alternative Proposal" which outlined how all citizens presently living at M.D.C. could be living throughout

Manitoba in a range of community settings. This included a listing of all existing community agencies which had committed to provide and support these settings. It also suggested forming a new agency in Portage la Prairie to govern those core services and staff remaining in that city and a government-community-university Task Force to oversee the transition.

- Actively supported the independent efforts of the organizations made up of people with intellectual disabilities (People First –Canada and Manitoba) as they also attempted to persuade the Manitoba Government not to entrench institutional living in Manitoba. This included their Yellow Ribbon campaign, two rallies at the Legislative Buildings and environs, and a candle-light vigil at the Manitoba Developmental Centre.
- Sponsored a two-day Forum where experts, parents and consumers from across North America spoke to the public and politicians of their positive experiences living without institutions. There were no Government Members of the Legislative Assembly in attendance at this Forum.
- Mailed thousands of post cards to Premier Gary Doer and Family Services and Housing Minister Christine Melnick
- Brought together religious bodies, social agencies and social justice groups to study the Government action and the community alternatives. They subsequently endorsed a collective statement to Government asking them to reconsider the entrenchment of institutions in Manitoba for citizens with intellectual disabilities.
- Accepted all invitations from media for information and interviews.
- Studied legal and Charter challenges to the Government decision to continue institutionalizing citizens.
- Joined and collaborated with a recently formed, multi-agency group coordinating actions to deal with "poverty and social exclusion" in Manitoba.
- Wrote "letters to the editor", some of which were published in local newspapers.
- Met with Minister Christine Melnick, her Departmental officials, the Premier's Chief of Staff, and Members of the Legislative Assembly.
- Produced a newsletter publication *"Opening Communities — Closing Institutions"* which featured articles from many different perspectives reflecting on the fullness of life within the community. This newsletter was distributed widely, including a personal delivery to all Members of the Legislative Assembly.
- Received support letters from Associations for Community Living in other provinces, from internationally-respected experts in the fields of disabilities, inclusion and de-institutionalization and from the National Task Force on De-institutionalization.

- Convened regular meetings of those agencies and organizations most active in the support and advocacy of Manitoba citizens with intellectual disabilities and kept information and communication lines open and active amongst all supporters of community living.
- December 3rd Candlelight Vigil organized by People First – MB at the Manitoba Developmental Centre in Portage to commemorate the United Nations International Day of Disabled Persons
- June 28th Social Justice Coalition issued a "Statement of Protest" over the Government's $40 million plan for renovation and rebuilding at Portage. Statement was signed by the United Church, Anglican Church, Mennonite Central Committee, Social Planning Council, several community agencies in the disability field. Media coverage was very solid
- Accelerated Pace Process – A slow, grinding process started by Family Services and Housing last February 2005. Only two people moved by planning up to March 31, 2006. A third person has now moved (July 3) and seven more people are actively being involved in planning for community support. A fraction of the $1.5 million committed has been spent.
- Community Living's fourth proposal to move a significant number of people from MDC was rejected in May 2006. Community commitments and $150,000 of funding from the community makes no difference.

Throughout these months we have supported each other in maintaining a spirit of hope and optimism that community life will actually become an option for all Manitoba citizens, despite the continued refusal of the Government to consider any other alternative than to continue to institutionalize large numbers of Manitoba's citizens.

ALBERTA UPDATE

Submitted by Norm McLeod

Michener Centre (including Youngstown) is a 24-hour institution housing about 346 individuals with developmental disabilities. The average age of the people living at Michener is 54. Forty-five people are 70+ years of age; five people are under the age of 30. Over 150 people have lived at Michener for more than 40 years. Seventeen people passed away between June 2005 and June 2006

Last year 12 people moved from Michener to the community. Two people have moved this fiscal and another ten individuals have expressed interest. There have been no admissions to Michener Centre in the last year.

Michener Centre announced on January 24 that it will be an active partner with the David Thompson Heath Region in developing a 280 bed continuing care centre, plus at least 45 independent housing units for seniors. Seniors currently living in Red Deer will be accommodated in first phase of the project. The development will be located on 13 acres of vacant land at Michener. Construction will start in the fall and be ready for occupancy late in 2008. The Health Region has agreed to include in the second phase accommodations for 50 to 70 individuals from Michener who meet the requirements for continuing care. Accommodations could include the development of townhouses. No timetable has been set for the development of the second phase of the project.

SASKATCHEWAN UPDATE

Submitted by Laurie Laison

Deinstitutionalization remains a priority for the Saskatchewan Association for Community Living (SACL), as all individuals, regardless of the level of their disability, can be and have the right to be included in society. With the proper accommodations, every citizen is capable of living a successful life in a home of their own.

This year, SACL partnered with People First of Saskatchewan to create the Deinstitutionalization Coalition of Saskatchewan (DCS). As founding members of the coalition, we are in the process of recruiting other organizations that are also concerned with the continued existence of institutions in our province and who are willing to commit to advocating for alternatives. Including new members in the coalition is our main goal for the summer and fall of 2006.

As a coalition, we have established a vision and mission, and have adopted the PFC/CACL Task Force definition of an institution, including large and small facilities that are institutional in practice. We have begun to develop communication materials, gather data about the range of institutional placements and are planning strategies to engage decision makers and the community in our efforts. We are developing goals and objectives for the year, which will include drawing attention to the gaps in services and advocating for funded, appropriate community supports as an alternative to institutionalization.

NOBODY WHO LIVED THERE AND GOT OUT HAS EVER SAID, ‘BOY, I’D REALLY LIKE TO GO BACK AND LIVE THERE AGAIN.’ NOBODY. NOT ONE. THAT TELLS YOU SOMETHING.
Bill – a former resident of Valley View for 42 years.

The coalition is actively positioning our province to confront, come to terms with and address why there are still people with intellectual disabilities housed in institutions in 2006. As John O’Brien has pointed out, 1972 marked the year that the argument could no longer be made that institutionalization was necessary. In that year, in every single case where it was argued that a particular person could not function or be supported in the community, and therefore must remain in an institution, advocates could point to a person with parallel complex, high needs living successfully in the community. Why, 34 years later, are we still fighting an outdated practice of incarceration in institutions?

Given the history of closures in other provinces and the evidence that a home in the community is less expensive than institutionalization, it is obvious that the only thing that keeps people isolated in institutions in 2006 is the lack of commitment to change. The driving force behind the Deinstitutionalization Coalition of Saskatchewan is to ensure that those Saskatchewan citizens who have been left behind, forgotten in institutions and whose human rights continue to be violated, have the opportunity to live supported in the community.

DCS Vision: *That all individuals will live in the community with the supports they need and the quality of life that they desire.*

DCS Mission: *On behalf of individuals who have an intellectual disability and who live in institutions, we will facilitate and ensure that they have access to a life in the community where they can exercise control over their lives.*

SOME PEOPLE JUST DON'T GET IT

Submitted by Harry Wolbert

When it comes to the topic of deinstitutionalization some people just don't 'get it'. This is a question that I have often asked myself and wondered why. Maybe you have too.


Harry Wolbert

Well I do get it! I remember a time in my life when I was institutionalized and denied my rights as a full citizen of this great country. So I know what I am talking about. What is it like being locked up and institutionalized? Many of the rights and freedoms which I enjoy today were taken away. I was stripped of my privacy, the right to make 'choices' or have any sense of control over my life. Some of the same fears, prejudices and attitudes toward persons with disabilities which were so prevalent back then are still around today.

When addressing the whole issue of deinstitutionalization we need to ask ourselves two questions that are at the very heart of the issue. They are 'whose life is it?' and who should have the power and control over that life?' How we answer these questions will determine which side of the fence we are on. Should it be the state? Non-government agencies? An individual's natural family? Or should it be the individual himself who determines the course and direction of his life?

More often than not money (or a lack thereof) seems to be one of the major stumbling blocks to achieving our goal of full citizenship for persons labeled with a disability. But is money the real issue? In my opinion it is not, nor should it be. After all the government of Manitoba was able to find 40 million dollars which it plans to put toward the upgrade of the Manitoba Developmental Centre located in Portage La Prairie. Why? In a day and age where we've closed down all of our orphanages and residential schools this government continues to fund and support an outdated system of care that other states and provinces (like Newfoundland and Labrador, and British Columbia) have now rejected too.

'AM I SAD? SAD....YEAH REALLY, YEAH REALLY, YEAH REALLY. I MISS THE LAST PLACE I LIVED. DO I EVER GO OUT TO DO ANYTHING LIKE WATCH A HOCKEY GAME? I WATCH THAT IN T.V. BUT NO, I DON'T GO OUT.
Jim - PEI

What will it take to get through to these individuals? It won't be easy. First we need to make it clear that we aren't going to go away. We will not rest until the Manitoba Developmental Centre and every institution like it is closed down. Permanently! Governments come and go. Whether it's this government that does it or some future government we must never lose sight of our ultimate goal. That all persons labeled with a disability have the opportunity to live in the community as full citizens. Nothing less!

A final word to our elected officials. Enough is enough! It's time to walk the talk. There are some really good policy papers (and studies to back them up) out there. We've also heard some inspiring messages on inclusion and full citizenship. These words need to be backed up with action and adequate funding. No more empty promises. The time to act is now!

ECCL SUPPORTS DEINSTITUTIONALIZATION

Submitted by
Ines Bulic, Coordinator
European Coalition for Community Living
Brussels

Across Europe, thousands of individuals still spend their lives segregated in institutions for people with disabilities. With a lack, or complete absence, of community-based services in many European countries, a large number of people with disabilities have no access to quality alternatives to institutional care.

The European Coalition for Community Living (ECCL) was founded in August 2005, to advocate for the right of all disabled people to live in the community, as equal members of society. The need for such an initiative was first demonstrated by the findings of the Included in Society project, which conducted research into institutions and community-based services in a large number of European countries.

ECCL is a cross-disability initiative and it was established by Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network of Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative. Our mission is to work towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalization.

As a Europe-wide initiative, ECCL advocates for the development of community-based services across Europe, and for the adoption of policy and action plans that will facilitate this process. In addition, we plan to campaign against the building of new institutions and carry out awareness-raising activities about human rights violations committed in institutions for people with disabilities. An important part of ECCL's work will also be lobbying for independent quality monitoring systems, oriented towards a better quality of life for people with disabilities.

As a growing network of disability and service provider organizations, academic institutions and others, ECCL is also in a good position to directly contribute to the efforts of its members, when it comes to the promotion and provision of community-based services. To this end, we believe it is important to follow the developments in de-institutionalization in different European countries and facilitate exchange of best practice, as well as tools and instruments used in the process of de-institutionalization and the development of community-based services. This and other useful information will be available from ECCL's new website www.community-living.info.

> **I WISH SOMEONE COULD GET ME AN APARTMENT IN THE TOWN. PLEASE GET ME OUT OF HERE, BECAUSE I DON'T LIKE IT. THERE'S TOO MANY PEOPLE. TOO MANY. TOO MUCH EVERYTHING HERE.**
> *Karen - PEI*

The first public event organized by ECCL was The Right to Live in the Community Seminar, which took place on May 17, 2006 in Brussels, Belgium. This very successful event brought together representatives of disability and user organizations, service providers, research institutions, governments and the European Union. Its aim was to provide an opportunity for participants to consider and discuss the key issues and challenges in the development of community-based services for people with disabilities in Europe and help ECCL formulate its strategy. The seminar participants endorsed the importance of ECCL's work and made a number of recommendations for a European strategy on de-institutionalization and suggestions for the future work of the Coalition.

Following the seminar, ECCL has continued with another important activity — increasing the number of its member organizations. We are now represented in twenty European countries, but our aim is to have an even larger membership, to ensure that our message reaches further. We believe that this and the other activities are crucial to build a network of organizations and individuals working towards the same goal of community living for people with disabilities in Europe.

For more information about ECCL's activities and membership possibilities, please visit our website or write to Ines Buliç, the ECCL Coordinator at coordinator@community-living.info.

Editor's note: The ECCL has followed the work of the People First of Canada-CACL Joint Task Force on Deinstitutionalization and very much agrees with the definition of an institution used by the Task Force. The ECCL has in fact adopted our definition, in a modified form, for its work. ECCL has broadened the definition to include all the people with disabilities, considering that it is a cross-disability initiative. The ECCL has used our definition in their documents, with a reference to the Deinstitutionalization Task Force and have also made it a part of their mission statement.

Fred Ford and Peter Bourne

CLOSE THE DAMN THING DOWN

Submitted by Peter Bourne and Fred Ford

Peter Bourne and Fred Ford are B.C.'s representatives on the Task Force on Deinstitutionalization. Peter is a singer, guitarist and an active community volunteer in Victoria. Peter has lived in institutions and he feels strongly that all people with disabilities should be supported to live in their own homes in the community. Fred is the Executive Director of Mary Manning Centre. He began to learn about the institutions when he worked at Huronia Regional Centre in Ontario in the early 1970s and he has been an advocate for deinstitutionalization and community living ever since.

Peter and Fred: We would like to help other people get out of institutions and we think it is important to help Canadians right across the country to understand that the community has everything a person needs and that all institutions in Canada should be closed.

Fred: When I hear about provinces investing millions of dollars in institutions or people fighting against institution closures, it helps me to remember Peter's unique brand of advocacy and also, that the deinstitutionalization movement is like other civil rights movements where the battle is never really over and where advocates face setbacks and barriers that seem insurmountable.

Peter: I can't see people's facial expressions, so I try to touch people's hearts with my singing. I can sometimes give people an inspiration with my singing. Some people might say, how can a blind person have the qualifications to be a leader? I think I do but I don't have a lot of schooling. What do you think? I think so. People can know from their own experience. I have come from a long way. I've lived in a lot of places and I know where I'm coming from. When I was young, my parents tried to make sure I had the very best. But in those days they didn't have much in the community for blind people. In the 1950s, I lived at an institution in Nova Scotia, then at Jericho Hill School in Vancouver and then at Woodlands Institution in New Westminster for nine years in the 1960s.

Fred: In BC, even though all of the large institutions for people with developmental disabilities have been closed, there is still much to be done. Deinstitutionalization means much more than just closing big institutions. Some of the challenges we face in BC include helping people with developmental disabilities to get out of other kinds of long-term care facilities and psychiatric institutions, ensuring that all people are well supported in the community and ensuring that people who were harmed when they lived in the institutions receive justice and restitution.

Peter: We hear from people on the Task Force that the government of Manitoba is putting forty million dollars into the institution there — I disagree — it's a waste of money. The politicians in Manitoba need to listen to people with disabilities. They need to put that money into community services for people with disabilities, jobs and meaningful activities in their communities. They need to open the doors to community and close institutions once and for all. People blossom in the community! We are human beings and we should be part of the community like everyone else. Fred and I have also talked about the situation in Ontario — about staff and families saying people need the institution. They are wrong! Everyone can live in the community, even people who need support 24 hours a day —people with all kinds of disabilities live in the community. There is nothing that the institution can do that the community can't do better. I say 'close the damn thing down' because it's not good for people — they lose their independence, it's not good or healthy for people to be in the institution.

I'D LIKE TO GET OUT MORE, I GUESS. SOMETHING LIKE SHOPPING OR COFFEE. THE THING I LOOK FORWARD TO THE MOST IS GOING OUT SHOPPING AND STUFF LIKE THAT. I LIKE IT WHEN I GO TO TOWN. I DON'T DO IT OFTEN. WHAT DO I WISH I COULD DO? I'D LIKE TO DANCE.

Gladys - PEI

Community agencies aren't perfect either, you see. Sometimes it takes a while to find the right living arrangement in the community — but if something doesn't work out that doesn't mean that the person needs an institution. I lived for a while in a place where I wasn't treated well. A social worker from the CNIB she said to me, 'are you willing to take that step, to pay your own rent and live on your own?' It was a scary step for me but I'm glad I said yes, because if I'd said no, I don't know where I'd be today. My moving days are over. I pay my own bills and I go to bed when I want to. The best thing is I don't have to get permission. I let people know where I'll be and how long I'll be gone — it's courtesy. I love having my own room, taking a shower when I want, having my privacy when I'm having a phone conversation with somebody and playing my music.

Peter and Fred: We both feel that the time has come for Canadians to demand that all institutions in Canada be closed, for governments and communities to support all people to live in their own homes in the community and for governments across the country to participate in a constructive process to acknowledge and make amends for the harms done to people in Canada's institutions. We also need to teach people about the institutions. We'd like to see people take courses about the institutions — in primary schools, high schools and universities. We don't want them to have nightmares, but if they don't learn about it, people will again try to say that institutions are a wonderful thing. They aren't! We need to get away from that kind of thinking by making sure people know what it was like. The younger parents need to learn about it too. More doctors and the medical community need to know more and do more to support community living. Society needs to be educated that institutions are not the way to go — we need to speak out, not let things slide back.

Peter: I believe in doing something. I don't believe in sitting back doing nothing. I don't want to sit back, knowing where I've come from. We need to let people know we are human beings. Some people say, 'let that go', when someone says something like 'we're going to have institutions again'. I sang *We Shall Overcome* on the radio because it reminds me of Dr. Martin Luther King. He wasn't disabled, but he knew what it was like because people hated him just because of the color of his skin. I sang it because it shows that we self advocates are not afraid to speak out. I spent almost nine years in Woodlands, some people spent all of their lives in the institutions and we can't let that happen any more.

LEARNING FROM OUR PAST

Submitted by Barb Horner

When my family and I moved to Nova Scotia in 1989, we were advised by the Department of Community Services that we could access $52.50 per month to care for our daughter Mallory in our home, or she could reside at the Dartmouth Children's Training Centre. Because of Mallory's on-going differing needs, we knew that we could not care for her at home with the assistance that was being offered. We were given no other options and due to our naiveté at the time and being new to the province, we held hope that a "training center" would indeed be beneficial for Mallory and we made the difficult decision to place her. We learned very quickly that even though she was home with us every weekend, had drop-in visits during the week, volunteered regularly at her school setting, spent every vacation with us, there was something missing from her life — for us and for her. Our life was in a constant turmoil without her in it everyday. The Training Centre could not offer her the individualized support which we felt was essential for her personal growth and it was so difficult as a family to be separated from her. Even today, it is painful to remember the emptiness that I felt as Mallory's mom — always feeling inadequate as a mother and completely alone and isolated with our concerns about Mallory's care. We felt so helpless and on our own when trying to address these on-going issues that we had for Mallory's safety, dignity and human rights.

On April 15, 1993 our life changed forever. Although there were on-going issues of injury and negligence — even with our constant presence in her life — our worst fears had come true. Mallory received second-degree burns and in less than 24 hours we knew that she would not return to the Training Centre. Even though we were initially thrown into a state of crisis, it forced us to quickly organize a support system around our family and to begin planning for Mallory's future at home.

After much research and support planning we presented a "plan" to the Department of Community Services to enable us to access individualized funding. Over the years, this individualized funding has allowed us to develop a support network around us as a family. We have joined a Co-op that provides self-managed living options for individuals with disabilities. Right now the Co-op assists us in finding support workers/attendant care for Mallory by advertising, conducting the abuse and police checks, short listing, and assisting with the interview process; they provide us with on-going coordinator support; a social network for both Mallory on an individual level and us as a family; and provides us with a safety net in regards to Mallory's care.

Mallory has a support team of four people who have been with our family for up to eight years. This team provides after school support, weekend social outings and out of home respite. I never dreamed that our lives would be so enriched and healthy as a family unit because of Mallory, the wonderful people in her life and because we have been empowered to create a support system around us that truly meets our needs — our needs as a family and Mallory's need to begin her independence away from us.

We are so fortunate. We have had the opportunity to have Mallory at home with us and have watched her progress with pride. Because we have been healthy as a family we have never lost sight of the value and worth of Mallory's life and know what we want for her future. Never again will we make the mistakes of our past and be forced into making decisions about Mallory's care that will put her at risk. She is too vulnerable.

We have had many opportunities to truly appreciate Mallory and to fall in love with her over and over again as she continues to amaze us with her strength of character, tenacity, sense of humor, determination and her desire to be heard. She has thrived by being a member of her community, attending her neighborhood schools in inclusive settings, establishing friends and relationships with peers who have made a commitment to her and her future.

Mallory's future lies in her community where she will continue to spread her wings, find her rightful place, contribute, participate and belong. As her family we will settle for nothing less.

HURONIA REGIONAL CENTRE

Submitted by Marilyn Dolmage

Peter Park recently reminded me of our unofficial tour of Huronia Regional Centre five or six years ago. Because I worked at "HRC" from 1968 until 1973, and because I have friends and colleagues who once lived there, I can show visitors corners of the property that are not part of any official tour. (My brother Robert — who I never met — died at the age of 8 in what was then called a "hospital school". Ironically, he never attended school and died of pneumonia, without penicillin).

People who grew up in Orillia still refer to the institution as "Out There". It is located on the shores of Lake Simcoe, surrounded by vast — and empty — expanses of lawns. When it was built in the late 1880s, it was remote, but it has always been vital to the city's economy; now it is on a busy route into the city. Across that road was once a large farm, where people with disabilities were required to work very hard (for packs of tobacco) and their produce subsidized various government institutions across the province. People have told me they were frightened of "the farm side", as children growing up at HRC — perhaps especially because it was also the burial ground for those whose family claimed them, neither in life nor in death.

When Peter and I visited the HRC cemetery, there were some numbers scratched in concrete, some stones with names engraved, and a couple of small, more personal markers, one of which was decorated with flowers. A large monument was placed there when the cemetery stopped being used in the early 1970s — "to all whose lives' journeys ended here". The cemetery was used for almost 90 years, and it is obvious that many more people were buried there whose graves remain unmarked. The strangest thing to see is that a number of the early grave markers have been cemented together as if marking some sort of mass grave. Years ago, I was told that these crude concrete slabs had been found during reconstruction elsewhere at the institution, where they had been overturned and re-used as patio and sidewalk pavers. I always had the impression that staff might have taken some of the stones home too — since many still seem to be missing.

Peter told me that a Memorial Park is opening in British Columbia — dedicated to all the people who died at Woodlands Institution. Institutional behaviour must be similar across Canada, because Woodlands' grave markers apparently also came to be used as paving material by staff, which has been an ongoing issue for the community living movement in BC.

Woodlands has been closed for ten years, but people still live and die at HRC, at least for a few more years. I have often said that there needs to be some recognition of what transpired there — like a Holocaust memorial, really. Very few people seem to know about the HRC cemetery, not even those who pass the site every day to teach and to learn in the Developmental Service Worker and other programs at Georgian College, less than half a kilometre away. I can be reached at inclusion@sympatico.ca or at 416-531-8553 if anyone wants to find a way to honour the people who died in Ontario institutions.

We need to share information across Canada about the harm of institutions — of all kinds. If we do not understand the past, we are surely doomed to repeat it.

APOLOGY NEEDED

Submitted by David Jory

Imagine what it would be like if people thought: "That person is specially favoured by God" when they saw a person with a disability. Think of all the respectful treatment, the fine clothes, the wonderful food, the beautiful house that person would get. All that would be "normal". In some places in olden days that is what happened.

In North America almost 100 years ago (around 1906), doctors and psychologists decided to call people with intellectual disabilities and people with mental health problems "threats to the purity of the white race". That is when really bad things started to happen. Before that, institutions were sometimes (just sometimes) places where people with disabilities were decently treated, helped and protected. Not after 1906. Hellish abuse — sometimes called "treatment" — and hellish living conditions became "normal" in institutions.

Much later on, the Government of Canada forced aboriginal children into residential schools so they would become "normal", like "white" Canadian children. Most of these schools were run by churches. There was lots of abuse of all kinds in these schools but some aboriginal adults have good memories of kind teachers and good treatment in them. Now the Government of Canada has apologized to the aboriginal people who were forced into those schools and the churches have apologized for what they were responsible for. Very big sums of money are being paid out to victims of those schools.

Everybody now knows that residential schools for aboriginal children and what happened in them were wrong.

Institutions for people with disabilities — and segregated classes and segregated schools — started long before residential schools for aboriginal children and they still exist; thousands of people are locked up in them today and too many are still abused. Provincial governments decided to do this and they decided to let doctors and psychologists have the final say in what went on in institutions, who was put in them and who came out and when. We have the same system today.

Psychologists invented "tests" and "assessments" which they said would tell the doctors who should be put in an institution. These "tests" and "assessments" are about as useful and real as what magicians used to read in tea-cups or the innards of animals. But doctors and provincial governments still go along with what the psychologists say.

The doctors and psychologists have never apologized for what they did — and still do. Neither have provincial governments, even those who have closed their institutions for people with intellectual disabilities. These three groups — provincial governments, doctors and psychologists — were, and still are today, responsible for the abuses that happened and still happen in institutions. They are the ones who decided that people with disabilities are "bags of deficits", "sub-normal", "threats to the purity of the white race"; they could have decided that people with disabilities are "specially favoured by God".

Aboriginal people got an apology from the Government of Canada and from the churches which ran the residential schools for aboriginal children. The aboriginals who were abused in those schools are given help to get over the abuse and get their lives together in their home communities.

But what about the children and adults with intellectual (and other) disabilities who were put in institutions? They were (and still are) victims of much worse abuse over many more years. Is getting them out enough? Should we not be looking for an apology from the provincial governments, the psychologists and the doctors? And for them to admit that it is wrong to put people in institutions just because they have an intellectual disability?

It would not be easy to do and it would take time but maybe we should think about it.

WOODLANDS MEMORIAL GARDEN

On July 7th, members of the National Task Force had the opportunity to visit the Woodlands Memorial Garden site. Hosting the visit were representatives of the BC Association for Community Living (BCACL) and the BC Self Advocacy Foundation (BCSAF), landscape architect Erik Lees, and many of the volunteers who helped create the Woodlands Memorial Garden.

Although BC's last institution — Woodlands — closed in 1996, a cemetery on the Woodlands grounds remained a sore point for former residents and family members. It is known that between 1920 and 1958, the over 3,000 individuals who died while at Woodlands or Essondale (now Riverview) were buried in the cemetery. In 1976 the cemetery was officially closed when construction began nearby for an extended care facility. Over the years all except a very few grave markers had been taken away — many were recycled and used as paving stones; some were even used to build a patio and barbeque firepit right on the Woodlands site. Its existence was virtually erased as the gravestones were removed and the area eventually turned into a park.

Reclaimed grave markers - Woodlands.

BCACL and BCSAF have worked, with support from the BC government, to restore the cemetery and to create the Woodlands Memorial Garden. Part of the work was to salvage and create an inventory of as many cemetery grave markers as possible. Through the work of many volunteers, over 400 grave markers have been discovered and these will be returned to and displayed at the cemetery as part of a series of memorial walls. The site is anticipated to be officially opened in the Fall of 2006, and is intended to honour the memory of those who lived in the institutions and those who were buried at the site, and to ensure that what we know about institutions is not forgotten.

DID YOU KNOW?

- ✔ As of fiscal 2001-2002 there were 948 residential care facilities with four or more beds for people with intellectual disabilities in Canada. There was a period of growth in the numbers of such facilities from 1986 to 1993 (from 840 to 1359), after which the number decreased to the present level.
- ✔ Nearly 15,000 people lived in residential care facilities for people with intellectual disabilities in 2002, down from 19,000 in 1986.
- ✔ Facilities that house four to nine people are more commonly used now than in the mid-1980s, but significantly less so than in the early 1990s. There has been a significant increase in the percentages and numbers of people living in facilities that serve from 20 to 49 people and from 50 to 99 people.

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.

✔ Overall, the entire 'system' of group homes and other facilities that serve four or more people with intellectual disabilities actually serves about 4,000 fewer people now than in the mid-1980s.

✔ Within Canada, the number of large facilities with 100 or more beds decreased from 4% of all facilities for people with intellectual disabilities in 1986 to 2% from 1990 afterwards.

✔ Research data indicate a clear trend towards increased use of smaller facilities from 1986 to 1993, then a reversal of direction somewhere after 1993. Having said this, facilities with four to nine beds comprised a greater share of all facilities for people with intellectual disabilities in 2002's smaller system than was the case in 1986. The proportion of people living in facilities this size was 23% in 2002, up from 18% in 1986. Density in places this size decreased from 6 people on average in 1986 to 4.9 people in 2002.

✔ There were more facilities with 4 to 9 beds in 2002 than in 1986 (679 compared with 562), but decreased from the number in 1993 (1,088). About the same number of people lived in such facilities in 2002 as in 1986 (3,325 compared with 3,398 respectively).

✔ In 2002 more people were living in facilities with 20 to 49 beds and in facilities with 50 to 99 beds (as compared to1986). These comprised greater percentages than previously of all residential care facilities for people with intellectual disabilities and the total numbers of such facilities have increased since 1986. The percentage of people living in facilities with 10 or more beds dropped from 82% in 1986 to 70% in 1992 then climbed back upwards and has hovered between 76% and 77% in recent years.

✔ Available data indicates a decrease in the total number of people living in residential care facilities of all sizes and thus suggests a constriction of the capacity of that system to respond to housing and support needs. Constricted capacity is also suggested by the density of living arrangements, which has been on the rise since 1992, particularly in facilities with 20 to 49 beds. Fiscal pressures and economies of scale may be driving governments to use residential care facilities with more than 20 beds and fewer than 100 instead of the much smaller more individualized arrangements that champions of deinstitutionalization would prefer.

✔ If you are a child with a disability living in the Central and Eastern European States, or in any of the other Community of Independent States, you have roughly a 18% chance of being placed in institutional care. For the child population as a whole, there is just a 0.39% statistical likelihood of being placed in an institution. This represents a massive 46-fold increase in the chance of being institutionalized if a child has disabilities than if the child has no registered disabilities. (Source: 'Children and Disability in Transition in CEE/CIS and Baltic States', Innocenti Insight Series, UNICEF, 2005).

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'Life Landscapes' — Saskatchewan Advocate Stories of Success — published by the Saskatchewan Association for Community Living
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