

institution watch

PEOPLE
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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.

This is a newsletter
written and produced
by the People First of
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***"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



SUMMER 2011

MESSAGE FROM THE TASK FORCE

**Norm McLeod and Shane Haddad,
Task Force Co-chairs**

As our regular readers will know, the Task Force through this newsletter has placed an emphasis on urging our provincial and territorial governments to finish the job of closing the last of the large institutions for persons with intellectual disabilities in this country. However while such closures remain critical, they should not be our only focus. Increasingly, individuals with intellectual disabilities, their families and members of the community living movement tell us of situations where other forms of institutional placements are being offered and used as responses to the residential needs of people with intellectual disabilities. While these facilities were not designed specifically or exclusively to serve persons with intellectual disabilities they are certainly now being used more frequently for that purpose. So as we have witnessed the slow closure of institutions for people with intellectual disabilities we are also witnessing an increased usage of facilities such as Seniors Homes, Nursing Homes, Long Term Care facilities, Rehabilitation Centres, etc. as places in which to 'place' people with intellectual disabilities. Clearly this is not what we mean when we speak of deinstitutionalization.

In acknowledgement of the need to expand our message of full community living for all, and in recognition of Canada's ratification of the UN Convention on the Rights of Persons with Disabilities, the Task Force has recently revised its mandate and adopted a new name. On behalf of our parent organizations – CACL and PFC – the Task Force will now be known as the **CACL PFC Joint Task Force on the Right to Live in Community.**

The Task Force believes that, in order to exercise their right to live in community, it is essential persons with intellectual disabilities have:

- The right to choose where, and with whom, they will live,
- The right to direct and control the supports required to enable a meaningful life in community,
- The right to make choices, and take risks,
- Access to adequate levels of individualized funding,
- The necessary disability related supports needed to fully participate in the community,
- Recognition of the supported decision making model and support from friends/family/advocates (of the person's choice) necessary to ensure an appropriate planning process.

Through this change in mandate and our ongoing efforts we hope to get community, governments and service providers to understand that deinstitutionalization is not a process that substitutes one institutional placement for another and that living in community must mean that all people have real choices as to where and with whom they live. Choices that become real when accompanied by access to needed supports and services.

GUEST EDITORIAL

Rick Tutt, Chair, Community Living Ontario's Deinstitutionalization Working Group

DEINSTITUTIONALIZATION - THE SECOND PHASE

The community living movement has done a remarkable job of developing supports and opportunities for people to live and learn and work and play in their communities. For people with an intellectual disability, living in the community is now the norm in Canada, when once it was very much the exception. Yet, many of us are considering an important and somewhat uncomfortable question. **Has the community living movement done enough to ensure that communities are welcoming places for people who have a disability?** This question creates a healthy opportunity to look inward at what we have created and question if the services and supports created to enhance community living are perhaps unintentionally providing barriers to that goal.

One might call this the second phase of the deinstitutionalization movement! There are several influences that are helping me to focus my own thoughts around this important question.

The UN Convention on the Rights of Persons with Disabilities

In particular, Article 19 of the Convention, recognizes that people who have a disability have: the right to live in the community; with choices equal to others; have full inclusion and participation; choose where and with whom they live; have access to a range of supports to prevent isolation or segregation from the community; and have equal access to community services and supports developed for all people.

Given that the UN Convention binds States Parties (i.e. governments), should our movement not be using the Convention to monitor how well we are doing to facilitate welcoming and inclusive communities? We should all read the Convention and monitor our own activities while at the same time holding our governments accountable.

Keeping the Promises

I recently read a paper called *Keeping the Promises: Self Advocates Defining the Meaning of Community Living*. It reports on a summit organized by three U S self advocacy organizations (Autistic Self Advocacy

Network; Self Advocates Becoming Empowered; and the National Youth Leadership Network) to develop a response to the Centres for Medicare and Medicaid that had announced they would be publishing regulations defining the character of home and community-based settings. The advocacy organizations, as a result of their summit and subsequent personal interviews, discussed what community living meant to them in terms of: physical structure and size; rights and self determination; qualities and attitudes of providers; access to community; and support and access needs. The paper is highly critical of segregation, lack of control, restrictive rules, lack of choice, power difference, denial of choice in relationships, restraints, etc. The paper talks in detail of how these restrictions limit a good life in the community.

Not surprisingly the paper is supportive of issues such as choice, ability to take risks, respect, freedom from fear, making a contribution, access to community resources, and being part of the neighbourhood, etc.

This paper is a “must read” for anyone in the community living movement. It provides significant insight into how we have created services that separate and how we can change these services to be inclusive. To access the paper go to

<http://www.acf.hhs.gov/programs/add/adddocs/KeepingthePromiseofCommunitySABEFinalApproved.pdf>

Definition of an Institution

At the top of this newsletter are **59 powerful words forming the Definition of an Institution**. Created by CACL and People First of Canada, this definition helps us look at what we are doing for people...as opposed to what we are doing to people. The words apply equally to our community supports as they do to the large institutions that many provinces have so far refused to close.

In conclusion I would like to again state that our movement has done an amazing job over the past half century...we have created opportunities that our pioneering families might only have dreamed of. Of that we can be very proud!

But we have done so by constantly re-examining where we have come from, where we want to go and what we are doing. It is time to take a serious look at what we have created at the end of the first decade of the 21st Century. As mentioned in the title we might just call it **Deinstitutionalization – the Second Phase!** And in doing so we will continue to help create communities that are even more welcoming of everyone!

ARTICLE 19 OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

As most of us are aware, Canada ratified the UN Convention on the Rights of Persons with Disabilities in March 2009. This convention, in 50 articles, clearly articulates what existing rights mean within a disability context, and the ways in which these rights can be made real. And we in the community living movement had great hopes that it would usher in a new era where government and community would give greater consideration and effort to ensuring that the rights of people with disabilities were fully recognized and endorsed. Yet in the two years since its ratification, in Canada we have yet to witness any significant efforts toward using the Convention as a vehicle to advance and further entrench and make real the rights of persons with disabilities. Indeed there appears to be a certain smugness within this country, particularly at a government level that we are already in full compliance with the Convention and that as a country no real additional action is required.

In the following section we display each of the associated clauses of Article 19, and provide examples from provinces and territories, which we believe reflect compliance with the convention; and examples of situations, which from our perspective clearly violate both the intent and spirit of the Convention. It is

noted that this is not intended to be a comprehensive or exhaustive analysis of national compliance with the Convention but rather a quick snapshot of what is happening across the country based on feedback and commentary from our ACL and People First partners across the country.

'States Parties to this Convention recognize the equal right 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' (Article 19 of the UN Convention on the Rights of Persons with Disabilities)

1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

Encouraging Examples...

- There are only three large institutions (larger than 100 beds) for persons with intellectual disabilities remaining in Canada compared to 31 such facilities in 1986.
- Provinces such as Newfoundland and Labrador and British Columbia have closed all their large institutions of people with intellectual disabilities.
- Ontario closed the last of its large government operated institutions for people with an intellectual disability in March of 2009.
- In New Brunswick, an initiative is underway to move approximately 40 individuals with an intellectual disability out of a provincial psychiatric facility.



- In Alberta, Youngstown Home, a rural institution, closed in 2011 and the fifteen former residents moved to communities in three regions of the province.
- In Manitoba, \$2.1M (in 2011-12) will be allocated to support 16 individuals to move from Manitoba Developmental Centre (MDC) to the community.
- The government of New Brunswick has signed an agreement with NBACL to support a provincial Social Inclusion Program. This program operates in five areas of the province and focuses on developing supported living arrangements for people with an intellectual disability.

However...

- Three large institutions (more than 100 beds) for persons with intellectual disabilities still remain open in Canada. These include Valley View Centre (SK), Michener Centre (AB) and Manitoba Development Centre (MB).
- The government of Nova Scotia lacks any current deinstitutionalization commitment with institutions actively being built and/or renovated. The province of Nova Scotia views institutions as part of the acceptable continuum of residential services for persons with intellectual disabilities.
- In Nova Scotia hundreds of families/individuals are living in near crisis situations while waiting for appropriate residential supports. Many others are living in types of supportive housing unsuitable for their needs and detrimental to their health.
- The Riverview Residential Centre (in Nova Scotia) is 'Home' to 96 individuals with intellectual disabilities. A Report was commissioned after 22 incidents of abuse were reported at the facility.
- In Ontario, at least several hundred people are living in large congregate care settings such as Homes for the Aged, Psychiatric facilities, Nursing Homes, etc. for no reason other than their label of intellectual disability and the fact that they cannot access the supports they need from a more appropriate source.

- In every province and territory, far too often people are not living in homes of their choice or with people with whom they would like to reside. This happens because of lack of funding, inadequate supports or simply because of attitudes that do not take into account peoples' rights and the importance of choice.
- In Québec about 350 persons are still living in institutions.
- In New Brunswick people with more significant disabilities encounter difficulty in accessing individualized living arrangements (due to the potential cost of such arrangements).
- In New Brunswick, there is an ongoing practice of 'placement' of younger adults with disabilities (including people with an intellectual disability) in nursing homes. Currently, there are nearly 400 adults with disabilities under age 65 in nursing home facilities.
- In Alberta, an Administrative Review of Persons with Developmental Disabilities indicated the government's direct operations (institutions) supported less than 7% of the individuals supported by PDD but at a greatly increased cost. The Review's recommendation to explore opportunities to reduce or close the institution was not acknowledged as a priority in the Minister's action plan.
- In Manitoba there are 264 people living at MDC and 200 living at St. Amant River Road Place.
- The government of Manitoba continues to view congregated and segregated care as an acceptable option for people with intellectual disabilities.

2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Encouraging Examples...

- The vast majority of Canadian citizens who have an intellectual disability do live in the community
- Promoting the implementation of the UN Convention continues to be a priority for the Canadian Association for Community Living and People First of Canada, and our provincial/territorial partners.
- In Quebec, a guide, *From Dream to Reality*, has been produced which presents 12 alternative housing models. These models were developed by parents who want real homes for their adult son/daughter.
- In Alberta, the Persons with Developmental Disabilities Program (PDD) supports 9,300 adults with developmental disabilities, has a small wait list of individuals seeking support and a further small number of individuals who are receiving less support than they would like.
- In Saskatchewan, representatives from the Self Directed Funding (SDF) Advisory Table presented a position paper that expressed the desire to see SDF added as an option for individuals and families who wanted choice in receiving support from the provincial government. While the government stated reservations regarding SDF they did agree to continue to meet and discuss.



However...

- In Nova Scotia, individuals with an intellectual disability are offered up to 21 hours of support per week in their own home or community (Independent Living Supports program). Anyone needing more than this level of support is offered placement in an institutional setting.
- In Alberta, many individuals are deemed ineligible to receive funding as a result of a new government regulation (August 2009), which established an IQ score of 70 as a 'cut-off'. Individuals who do not meet this new eligibility requirement, some of whom are in extremely vulnerable situations, are unable to access necessary supports and services.

- The majority of provinces/territories have service ‘ceilings’ on the extent of in-home supports that can be made available to persons with disabilities. This means that many individuals (usually those with more extensive needs) are offered institutional placements rather than the supports necessary to live in community.

3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Encouraging Examples...



- In New Brunswick, the Disability Support Program provides access to individualized funding and opportunities for people to identify their goals and needs for support through person directed processes (including having access to an independent planning facilitator).
- In New Brunswick, the Social Inclusion program provides support to facilitate connections to community activities for youth and adults.
- NBACL has presented a supported employment framework proposal to government to move to an ‘employment first’ policy orientation. A research project is also looking at the potential for people to be engaged in community employment with access to additional employment supports.
- In Alberta, PDD is moving to ensuring all service contracts identify the individuals who are funded, the level of service being provided and the outcomes to be achieved.
- The Saskatchewan Assured Income for Disabilities (SAID), recently introduced in Saskatchewan, provides for a separate income support system for persons with disabilities. While promising, the SAID program has yet to make a significant difference in the amount or manner in which income support is delivered to persons with disabilities.
- In Manitoba community based services currently support approximately 5,000 people. The community agencies are a mix of well established long-term providers of support services, and younger agencies established in new communities or those offering new models of support to meet the unique needs of people. Among the thousands of people being supported in community are those who have significant health needs or whose behavior is described as challenging.

However...

- In New Brunswick, there is the continued ‘placement’ of people with an intellectual disability within segregated day programs (such as sheltered workshops, industries, or activity centres). Currently, there are hundreds of people still being served in these types of programs.
- In Alberta, PDD continues to fund individuals based on models of support rather than on individual choice of where and with whom to live. One of the preferred models, the ‘Supportive Roommate’ (typically has one individual living with a support person or family in their home in the community) has mixed results. For some it increases their isolation and results in a loss of autonomy.
- There are approximately 12,825 people with intellectual disabilities waiting for residential services, personal care / personal support services, and/or day programs; based on available data from Ontario, Quebec, Nova Scotia, Saskatchewan, Alberta and New Brunswick.
- In the Yukon, there is a critical shortage of accessible affordable housing

The foregoing provides a very brief and limited glimpse at our national reality as related to compliance with Article 19 of the UN Convention. While certainly as a country we have much to be proud of as related to supporting people with intellectual disabilities to live successful and inclusive lives in community, there are undoubtedly many, many examples of situations, policies and practices which continue to reinforce an institutional approach to community living.

THE CONVENTION REQUIRES FOCUS AND FORCE

People First of Canada

“Any community or neighborhood can be very institutional when people are not recognized as true citizens.” – Patrick Worth

Human rights are basic rights to which all people are entitled. These rights include the right to freedom and freedom of expression, along with political, civil, social, cultural, and economic rights. These rights are about our rights to be free and act for ourselves, to speak our minds, to be involved, to have food, water and shelter, to learn, to work, and to be active and included in the community and the world.

These rights are protected in such documents as the Universal Declaration of Human Rights and the Canadian Charter of Rights and Freedoms. These documents were made to protect the rights of every human, and to guarantee the rights and freedoms of all Canadians. Most recently, documents like the United Nations Convention on the Rights of Persons with Disabilities were made especially to protect the rights of people with disabilities. The Convention states what those protections mean and how options, choices, and opportunities need to be equal to those enjoyed by people without disabilities.

Human rights and the documents that protect these rights are good things for all people. They help us to understand the details that go with our rights. They also help us by providing a vision of human dignity that applies to all people.

The vision is both basic and ideal. The Convention’s articles speak to the rights to live in the community, to an education, to work and employment, to an adequate standard of living, and to participation in all aspects of society. The word ‘dignity’ appears in the preamble of both the Declaration and the Convention. Dignity is clearly seen as basic and fundamental to being human. It is unfortunate for people with disabilities that this vision has been blurred when it comes to dignity. It is unfortunate for people with disabilities that our rights are often forgotten or ignored.

For many people with intellectual disabilities, Article 19 of the convention – living independently and being included in the community – is the most relevant. This article promotes community living and ensures that people have the right to choose where they live and with whom, and, furthermore, that people are not obliged to live in a particular living arrangement if they don’t want to. This article also states that people with disabilities have the equal right to live in the community with the same choices that people without disabilities have available to them.

Like human dignity, living and being included in the community is foundational and basic. Many people with disabilities believe that living in the community is the cornerstone upon which other rights are built. When we compromise the choices and options available to people with disabilities, we blur the vision of human dignity and treat people as second-class citizens.

Human rights are many things, but ultimately, human rights are either respected or violated. Providing options, choices, and access to supports will go a long way towards focusing the vision of human dignity to clearly include everyone.



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 October 2011).

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.

ACKNOWLEDGEMENTS

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