



## Position Paper on Deinstitutionalization

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

### Introduction

- Deinstitutionalization of persons with disabilities began in Nova Scotia in the 1970’s.
- In 2 decades 5 adult institutions closed or were downsized and 5 Children/Youth Training Centers were shut down.
- The Minister’s Advisory Committee on Services to Children and the Regional Officials’ Committees (regarding adults) resulted in planned increases in community based residential services throughout Nova Scotia.
- In 1995 government released “Moving Towards Deinstitutionalization – A Discussion Paper”, in which the Department of Community Services communicated its desire to develop policy based on a vision of Inclusive Society and Empowerment and the principles of Rights and Responsibilities, and Participation.

The future for people with disabilities in Nova Scotia looked bright.

- In response to these initiatives community based services flourished.
- At first large group homes of 7 to 12 people opened, but soon the benefits of smaller, more individualized living arrangements became apparent.
- Small Options (now known as CBO’s) for 3 persons or fewer became the order of the day and some group homes were downsized. CBO’s, together with supported apartments, now constitute the bulk of residential services in the province.
- The non-profit agencies that manage these services make up NSRAA’s membership.

The transition from institution to community provided ample opportunity to witness the profoundly negative impact of large congregate living. It erodes the human spirit, diminishes well-being and self-worth, and decreases people’s value in the wider community. NSRAA recognizes the need to guard against replicating institutional practices in smaller community settings.

### Definition of an Institution:

***“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.” – People First of Canada – CACL Joint Task Force on Deinstitutionalization***

Unfortunately, deinstitutionalization efforts have all but ceased in Nova Scotia in recent years. This comes at a time when persons who have mental health concerns, intellectual disabilities and/or physical disabilities are virtually the only remaining group for whom systemic segregation and congregation continues in Canada. Over the last several decades Canadians learned important lessons about orphanages, residential schools and the like and moved to remedy such disenfranchising situations.

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

Why, then, is it still okay to institutionalize persons with disabilities?

### **Human Rights:**

On December 13, 2006, the United Nations General Assembly formally adopted the UN Convention on the Rights of Persons with Disabilities and Canada is a signatory to the Convention. The convention calls for signatory states:

- To take measures to ensure the full inclusion of persons with disabilities and their families.
- To develop legislation that will ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities, without discrimination of any kind.
- Specifically in Article 19, to recognize the equal right of all persons with disabilities to live in the community, to choose their place of residence and where and with whom they live on an equal basis with others, not being obliged to live in a particular living arrangement.
- To ensure full participation in the community and to prevent isolation or segregation.

The UN Convention sets a resounding stage for the abolition of institutions in Nova Scotia and Canada.

### **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.

## NSRAA Positions

1. NSRAA recognizes that as supporters to those receiving human services, **member agencies affect the daily experiences and the future prospects of the people, families and communities who rely on them.** They hold great accountability and have much influence on people's lives. The ultimate goal of assisting people to discover their intrinsic value as individuals and having this value recognized by the greater community, greatly depends on the policies and daily practice of each individual agency.
2. NSRAA understands that human service organizations can't manufacture better lives. **People weave better lives from the resources** afforded by individual effort, personal relationships, available opportunities, help from services and through collaboration between the person, family and friends, neighbors, classmates, coworkers, employers, and service providers.
3. NSRAA encourages member agencies to invent and provide **person centered solutions and responses** rather than simply selecting from a menu of existing services.
4. NSRAA is committed to building **more just and inclusive communities** and to supporting disabled persons in taking their rightful place in the community.
5. NSRAA supports the UN Convention and urges the **speedy development of federal and provincial legislation**, and the resulting closure of all segregated institutions for people with disabilities.
6. NSRAA does not support the Theory of the "Must Stay" Group. The classic four **reasons given for keeping people in large segregated settings** (severe disability, challenging behavior, medical fragility, and advanced age) **have been convincingly discredited** over the past 3 decades.
7. NSRAA understands that successful deinstitutionalization requires **passion and leadership** that is persistently focused on vision, principles, and purpose. NSRAA nurtures such passion and leadership in its membership.

## References:

### **This Position Paper draws on a number of sources including:**

Clemmer, Jim. (2007). Blazing Our Own Unique Leadership Path. CQL Newsletter. Winter, 2007. Retrieved May 1, 2007 from: <http://www.cqlcanada.com/NewRoom/NewRoom.htm>

Council on Quality and Leadership Canada. (2007) CQL Newsletters. Retrieved May 1, 2007 from: <http://www.cqlcanada.com/NewRoom/NewRoom.htm>

Government of Nova Scotia, Dept, of Community Services. (1995). Moving Towards Deinstitutionalization – A Discussion Paper. Nova Scotia, Canada

Inclusion International. Various Articles. Retrieved May 1, 2007 from: [www.inclusion-international.org/en/](http://www.inclusion-international.org/en/) .

Kendrick, M. J. (2001). An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System. Nova Scotia Department of Community Services, Nova Scotia, Canada.

O'Brien, John, Speaker and Author - Responsive Systems Associates. What's Worth Working For? CQL Newsletter. Winter, 2007. Retrieved April 23, 2007 from: <http://www.cqlcanada.com/NewRoom/NewRoom.htm>

O'Brien, John, Speaker and Author - Responsive Systems Associates. Various Articles. Retrieved May 1, 2007 from: [thechp.syr.edu/rsa.htm](http://thechp.syr.edu/rsa.htm) .

People First of Canada – CACL Joint Task Force on Deinstitutionalization. Institution Watch Newsletter, summer 2006, winter 2007. Retrieved May 1, 2007 from: [www.cacl.ca/english/mediaroom/instwatch/index.html](http://www.cacl.ca/english/mediaroom/instwatch/index.html)

United Nations General Assembly. December 2006. Convention on the Rights of Persons with Disabilities. Retrieved May 1, 2007 from: [www.un.org/esa/socdev/enable](http://www.un.org/esa/socdev/enable)

Wallace, B. (2005). Self-Management and Supported Decision Making – Our Search for Best Practice. Kendrick Report Coalition, Halifax, NS.

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