

# Deinstitutionalization: Making Community Living a Reality for *ALL*

“More than eight in ten [Canadians]... agree with the statement that persons with even the most challenging disabilities should be supported by public funds to live in the community rather than institutional settings...

From Environics, “Canadian Attitudes Towards Disability Issues,” 2004

## **Introduction**

We know that, when asked, people with intellectual disabilities choose not to live in institutions. We know that institutions deny people basic rights of citizenship, personal control, decision-making, and independence. Based on personal stories, as told by people who have lived in these facilities, we also know of the abuse, isolation and personal suffering that more often than not occur in these facilities. The institutionalization of persons with disabilities is a denial of their basic right of citizenship and participation in community. In a modern and just society, such as Canada, it is intolerable that people with disabilities remain trapped in institutions. The continued warehousing of individuals in institutions is a national disgrace and makes our national dialogue on rights and citizenship rhetorical.

Research has shown that the expectation that persons with disabilities should live in the community is not simply a vision espoused by families and individuals within the CACL and PFC movements. The vision of community living is held by the vast majority of Canadians. Renewed federal/provincial/territorial leadership and a commitment to the closure of all facilities is vital to ensuring that this Canadian vision is achieved for all our fellow citizens with intellectual disabilities. We must act now to fulfill a promise made many years ago.

## **What is 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.

Institutionalization represents an approach that denies choice, denies opportunity, that congregates, segregates, and isolates people. Institutions include all places where people are isolated, controlled, and where personal choices are not permitted. It is a place where you do not have control. Institutions deny you a life — they take away your ability to know and connect to your family — your community — deny you the opportunity for friendships. Institutions take away the ability to have responsibility for your own actions. An institution is a place where people are not permitted to dream.

## **Deinstitutionalization Efforts – What has been accomplished?**

During the 1990s, the federal government via its National Strategy for the Integration of Persons with Disabilities (NSIPD) Initiative provided transitional funding to many provinces and territories to advance deinstitutionalization efforts. This federal leadership strategy, complementary to ongoing provincial and territorial efforts, was highly successful and resulted in the closure of many institutions. Indeed, efforts resulted in the full closure of facilities

designed to house people with intellectual disabilities in several provinces, including British Columbia and Newfoundland and Labrador. These efforts clearly demonstrated that with appropriate planning and service provision, persons with intellectual disabilities, regardless of type or extent of disability, can leave institutional environments and take their rightful place in the community as full and participating members of society.

Deinstitutionalization efforts in Canada, in particular those achieved within the NSIPD Initiative, have provided key insights into what is needed to achieve success:

- Individuals and families, especially where children are involved, must be given status and support to exercise personal choice;
- Supportive relationships for people must be built that give people value and respect;
- Opportunities and support must be established for people to learn and work in the community;
- Community services and structures must be available and accessible (that is they must be usable by all people, free of barriers, etc.); and
- Flexible and responsive personal supports must be provided to meet disability related needs

### **Where we are Today**

During the 1990s the disability community was very encouraged by the closures (and/or accelerated depopulation) of facilities designed to house people with intellectual disabilities. With strong leadership being demonstrated by the federal government, provinces and territories made public commitments to continued deinstitutionalization efforts, and the signing of the historic *In Unison* agreement was a clear signal that institutions would cease to play any role in the lives of persons with intellectual disabilities. Unfortunately however the momentum created by and within the NSIPD strategy has, for a variety of reasons, clearly not been sustained. While institutional populations continue to slowly decrease in most jurisdictions efforts toward full closures in most provinces and territories have stagnated. Even more alarming, in at least one province, new investments are being poured in to refurbishing institutions. One notable exception is the 2004 announcement by the Government of Ontario to direct \$110 million toward closure of its remaining institutions.

More than a decade has passed since the NSIPD strategy, and its promise of full community living for all and still more than 14,000 persons with intellectual disabilities remain trapped in institutional facilities designed specifically to house persons with intellectual disabilities. Thousands more remain in health related institutions such as Senior's facilities, Nursing Homes, acute care hospitals, Long Term Care facilities and Personal Care Homes, as opposed to ordinary homes in the community. They are there not by choice, but rather due to a lack of efforts in this country toward creating the necessary planning supports, and needed community supports and services, to enable their return to the community.

### **A Snapshot of data**

Recent research by the Roeher Institute has demonstrated that:

- As of fiscal 2001-2002 there were 948 residential care facilities for people with intellectual disabilities in Canada.
- More than 14,000 people lived in residential care facilities for people with intellectual disabilities in 2002
- While general trends have indicate there has been a general decrease in the number of persons with disabilities living in institutions, in particular large-scale institutions, the number of residential care facilities in Canada has actually increased.

**Table 1. Numbers of residential care facilities for people with intellectual disabilities, by facility size, in selected years**

Facility size (number of beds)	2001- 2002	2000- 2001	1992- 1993	1990- 1991	1986- 1987
4 to 9	679	709	1,088	918	562
10 to 19	119	129	132	145	151
20 to 49	87	90	86	89	79
50 to 99	44	46	26	24	17
100 +	19	19	27	28	31
Total	948	993	1,359	1,204	840
100 to 199		10	10	16	14
200+		9	9	11	14

- General trends also indicate that while there has been a decrease in persons with disabilities living in large-scale institutions, there has been an increase in persons with disabilities living in smaller scale residential care facilities.

**Table 2. Numbers of residential care facilities for people with intellectual disabilities, by facility size, in selected years**

Facility size (number of beds)	2001- 2002	2000- 2001	1992- 1993	1990- 1991	1986-1987
4 to 9	72%	71%	80%	76%	67%
10 to 19	13%	13%	10%	12%	18%
20 to 49	9%	9%	6%	7%	9%
50 to 99	5%	5%	2%	2%	2%
100 +	2%	2%	2%	2%	4%
Total	100%	100%	100%	100%	100%
100 to 199		1%	1%	1%	1%
200+		1%	1%	1%	1%

### Why Institutions Remain a Problem

Community living has not become a reality for many Canadians with intellectual disabilities. There are many issues that contribute to this. While adequate funding and appropriate resources are critical factors, there are also fundamental values and beliefs that are needed to make community living a reality. A firm belief that *all* persons with disabilities not only have a right to live in the community, but that they *belong* in the community combined with the moral courage and political will to challenge the status quo are essential in making community living a

reality. Some provinces continue to believe that some people do not belong, or cannot, live in their community. The pervasive nature of these negative assumptions represents an invisible obstacle that must be challenged. We believe that it is once again time that the federal government assumed a leadership position with respect to this issue, in collaboration with, and in support of, provincial and territorial Associations for Community Living and People First chapters.

### **Moving Towards Full Closure**

Provinces and territories need assistance and motivation in transitioning from institutional systems of support to inclusive and enabling community-based systems. Such a transition requires both government and community leadership, a collaboration between individuals/families, community and government organizations, an availability of transitional funds (where necessary), and an agreement to redirect institutional funds to community supports. Most importantly, it requires that we place value on the lives of persons with intellectual disabilities, give importance to their role and potential contribution as Canadian citizens, and commit to a total rejection of institutions as an acceptable response to the needs of persons with intellectual disabilities. Together we can close institutions and make community living a reality for all.

### **Conclusion**

The time is long overdue to permanently remove institutions from the residential options offered to persons with intellectual disabilities. Clearly, persons with intellectual disabilities have rejected any role for institutions in their lives and instead are rightfully demanding that they be given the right to choose to live in the community. With this choice comes the demand for appropriate supports and services that will enable community inclusion and participation.

Canadians seek pride in the values of respect, dignity, and inclusion. To deny persons with disabilities the right to live and be valued in their community is a loss for all Canadians. Canadians with disabilities deserve better. Canadians with disabilities belong in their community.