

DEINSTITUTIONALIZATION

A Call to Action

Citizenship for Canadians with disabilities means a full recognition of equality rights, inclusion and independence for people with disabilities.

— *In Unison*

The institutionalization of persons with intellectual disabilities is a denial of their basic right of citizenship and participation in community. Institutionalization takes away rights as set out in such documents as Mainstream 92, In Unison, and as protected by the Charter of Rights and Freedoms, human rights legislation and many other international agreements that Canada has signed. The continued warehousing of individuals in institutions is a national disgrace. How can we speak of rights, independence and freedom when so many of our fellow Canadian citizens remain in such facilities.

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Why deinstitutionalization, again?

Despite the modest gains demonstrated during the 1980s and 1990s, thousands of people with intellectual disabilities remain trapped in institutional environments. 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. Activity directed toward further institutional closures in Canada has, for a variety of political, social and economic reasons, slowed down and/or stopped.

At the present time in this country...

- 1 Over 20,000 Canadian citizens are living in health related institutions such as Seniors facilities, Nursing Homes, acute care hospitals, Long Term Care facilities and Personal Care Homes, as opposed to ordinary homes in the community.
- 2 More than 12,000 persons remain trapped in institutional facilities designed specifically to house persons with intellectual disabilities
- 3 Many Provinces and Territories are beginning to move away from earlier commitments made to complete institutional closures; while others have yet to indicate plans to close facilities.
- 4 In at least two areas of this country new institutions are being built that will house persons with intellectual disabilities.
- 5 Current government policy in many provinces and territories restrict access to required funding and to the disability supports and community services necessary to community living.
- 6 More and more, individuals with intellectual disabilities and their families are presented with options that do not support lifestyles of choice but rather entry into group home programs and/or other places where people are congregated.
- 7 In many provinces and territories persons with intellectual disabilities are being admitted on a routine basis to institutions, directly violating a stated policy of deinstitutionalization.



What is an institution?

The CACL and People First Task Force on Deinstitutionalization defines an institution in the following manner:

“An institution is any place in which people who have been labelled 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.

Institutions are not new. This response by society assumed that services could be best, and more cheaply, delivered in large settings, that individuals did not have the necessary skills to live in the community, that they were not capable and needed to be cared for, and that disability was a flaw in the individual that could be corrected through appropriate training and modification. We now know all these assumptions to be false.

We have learned that:

- 1 People with intellectual disabilities, when asked, choose not to live in institutions.
- 2 Institutions deny people basic rights of citizenship, person control, decision-making, and independence. Based on personal stories, as told by people who have lived in these facilities, we know of the abuse, isolation and personal suffering that more often than not occurs in these facilities.
- 3 Limitations usually associated with disability are as much related to the surrounding environment and rules of society as they are to the individual.
- 4 People, regardless of type or extent of disability, do not need to live in institutions.
- 5 Providing service in the community is no more expensive, on average, than that provided in an institution.
- 6 People flourish and thrive when they live in the community, either independently or with support.

Efforts throughout this country during the past twenty years have clearly shown that the ability exists, through appropriate planning and service provision, to assist persons to leave institutional environments and take their rightful place in the community. We know that people, regardless of type or extent of disability, do not need to live in institutions. Most importantly, we know that people flourish and thrive when they live in the community, either independently or with support. We have learned from past efforts that deinstitutionalization is as much about supporting people to continue to live in the community (i.e. prevention) as it is about closing facilities. We know what is needed to achieve success:

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

Guiding Principles and Values

Renewed efforts to assist persons to leave institutions must be guided by those values and principles that are known to achieve positive outcomes.

Deinstitutionalization must be about more than simply closing large institutions, about more than simply replacing large institutions with smaller ones, about more than creating networks of group homes, and ultimately about more than substituting isolation outside the community for isolation within the community. A deinstitutionalization plan must ensure that people have:

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

A National Plan for Deinstitutionalization

A successful deinstitutionalization plan will require the partnership and cooperation of both levels of government, national and provincial/territorial advocacy organizations, families, friends and, most importantly, the full participation of persons who are currently residing in these institutions.

Such an effort will require an initial investment of new funds, and an agreement to redirect institutional funds to community supports. It will require 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.

Some of the primary parts of such a plan would include:

- I. An agreement developed in full consultation with federal, provincial and territorial governments, individuals with intellectual disabilities and representing advocacy organizations.
- II. A commitment by provincial and territorial governments to stop all admissions of persons with intellectual disabilities to institutional facilities.
- III. Setting of provincial/territorial priorities in consultation with individuals with intellectual disabilities, their families, and advocacy groups.
- IV. Funding by the federal government to enable provinces and territories to offset additional costs while they are closing institution(s) and developing community services.
- V. An “emergency fund” that when combined with provincial/territorial funds can be used to prevent possible institutional admissions arising from emergency situations in the community.
- VI. Redirection of all funding previously associated with the operation and administration of the institution to the provision and maintenance of required community living supports.
- VII. Funding for necessary research, collection and sharing of best practices, and follow up with people who leave (or have left) the institutions.
- VIII. Planning process that provides for the full participation of the person in all aspects of decision making, and the full participation of family, friends and advocacy groups as chosen by the individual.
- IX. Commitment to the establishment of reasonable time frames to close the institution(s) recognizing that planning may need to occur over a 3 - 5 year period, and creation of a monitoring/evaluation process with reporting procedures.

The Need for Action

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 appropriate community inclusion and participation.

Knowledge gained and results shown from previous efforts in this country clearly indicate that sufficient capacity and ability exist to assist people to leave institutions. It has been proven, beyond any doubt or debate, that persons regardless of assumed severity of disability can live in, and contribute to, the community. What we have failed to do, however, is translate these “lessons learned” into policy and practice. We have, despite a proven capacity and stated intent to do otherwise, permitted thousands of Canadian citizens with intellectual disabilities to remain sentenced to lifetimes of imprisonment in institutions. Simply, we have failed to do what we know can and should be done. It was important that we began this task — it is more important that we now finish it.