



Proposed National Plan on Deinstitutionalization Discussion Paper

Background

Persons with disabilities participate as full citizens in all aspects of society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well being through access to required supports and the elimination of barriers that prevent their full participation.

Vision Statement - In Unison

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

In Unison

People First of Canada and the Canadian Association for Community Living (CACL), and their provincial and territorial associations, have (re)established a relationship in order to highlight the continued and unacceptable incarceration of persons with intellectual disabilities in institutions throughout this country. Both organizations agree that 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. Both organizations agree that the continued warehousing of individuals in institutions is a national disgrace and, until corrected, makes meaningless much of the language surrounding the disability movement in this country that speaks of rights, independence and freedom.

Why deinstitutionalization, again?

Despite the modest gains demonstrated during the 1980s and 1990s, especially through initiatives within the National Strategy for the Integration of Persons with Disabilities (NSIPD), many 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. Since the NSIPD, and in contradiction to the positive outcomes achieved, activity directed toward further institutional closures in Canada has, for a variety of political, social and economic reasons, slowed down and/or stopped.

In 2002.....

- 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.
- More than 12,000 persons remain trapped in institutional facilities designed specifically to house persons with intellectual disabilities.
- 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.
- In at least two areas, new institutions are being built that will house persons with intellectual disabilities.
- 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.
- 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.
- 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 have we learned?

.....About institutionalization?

Institutions are not new. They have been in existence for hundreds of years. At one point, our society viewed them as the primary, perhaps preferred, residential option for persons with intellectual disabilities who could no longer live at home. 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 these assumptions to be false.

We have learned 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 know of the abuse, isolation and personal suffering that more often than not occurs in these facilities.

We also know that institutions are not defined merely by size. In the words of Mr. Pat Worth, Deinstitutionalization Task Force Chair, founding member of People First and CACL Director.....

“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.”

.....**About deinstitutionalization?**

We are now aware that the limitations usually associated with disability are as much related to the surrounding environment and rules of society as they are to the individual. We know that people, regardless of type or extent of disability, do not need to live in institutions. We know that providing service in the community is no more expensive, on average, than that provided in an institution. Most importantly, we know that 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 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. Evaluations of previous

deinstitutionalization efforts, particularly those achieved within the NSIPD Initiative, have provided key insights into what is needed to achieve success:

- Individuals and families (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.

In addition, previous efforts have clearly shown that success depends upon the establishment of several key building blocks. No one building block alone ensures successful outcomes. However, when present in combination, they create the necessary conditions that enable people to leave institutions and take their rightful place in the community in an inclusive and ongoing manner. These building blocks include:

- Ongoing commitment to the goal and vision of deinstitutionalization by all partners.
- Formal accountability plans.
- Individual planning, decision-making, and support network development.
- Development and management of individual supports.
- Structure and process for community development.
- Flexible funding plans.
- Forum for partnership.

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 exists 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.

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:

- The right to choose where they will live, and with whom;
- Services/programs that are directed and controlled by the person and that are respectful of that person’s 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 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:

- An agreement developed jointly and in full consultation with federal, provincial and territorial governments, individuals with intellectual disabilities and representing advocacy organizations.
- A commitment by provincial and territorial governments to stop all admissions of persons with intellectual disabilities to institutional facilities.
- Recognizing that residential services fall within the responsibility of provinces and territories -- a national plan must enable provincial/territorial priorities to be set in consultation with individuals with intellectual disabilities, their families, and advocacy groups.
- Funding by the federal government to enable provinces and territories to offset additional costs while they are closing institutions and developing community services. Funding will be negotiated between each province/territory and the federal government and will be available over a number of years.
- Funds transferred will also include 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.
- Agreement that all funding previously associated with the operation and administration of the institution be redirected to the provision and maintenance of required community living supports.
- Provision of funds to ensure that necessary research is conducted regarding the numbers of individuals, the type and locations of institutions, collecting and sharing of best practices, and follow up with people who are leaving (or who have left) the institutions.
- A planning process that provides for the full participation of the person in all aspects of decision making, and that enables the full participation of family, friends and advocacy groups as chosen by the individual.
- Establishment in each province/territory of a Steering Committee made up of provincial/territorial and institutional officials, members of People First and the ACL consumer and family representatives and representatives from the federal government, People First Canada and CACL. This Steering Committee will be responsible for development and management of the planning process.
- 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; establishment of annual “discharge” targets; creation of a monitoring/evaluation process, and development of necessary reporting procedures.

Actions required to implement a deinstitutionalization plan

Governmental level

- People First and CACL begin discussions with the federal government regarding the need to start deinstitutionalization efforts throughout Canada.
- Call on the federal government to consider the use of current federal transfer payments (CHST) by provinces/territories to maintain institutions as wrong.
- Request the establishment of a federal fund that will make available the transitional dollars needed by provinces and territories to close institutions and develop required community supports.
- All federal, provincial and territorial governments must recognize that the continued use of institutions as a residential option for persons with intellectual disabilities is in direct violation of their public commitment to principles of the In Unison document.
- Call on all provincial and territorial governments to announce specific “timeframes” for institution closures.
- Through discussions with provincial and territorial governments, call for immediate action to close existing institutions either through the use of existing funds and/or participation in the proposed federal transfer.

Organizational level

- People First and CACL through the establishment of a joint Task Force confirm their commitment to establish an ongoing relationship re: deinstitutionalization.
- People First of Canada and CACL:
 - issue a joint press release condemning the intent by the Nova Scotia government to build a new institution, and calling on them to in fact close the institutions that still remain open.
 - develop a joint statement on the continued use of institutional facilities for persons with intellectual disabilities and call for an immediate development of a national deinstitutionalization plan.
 - develop a working definition of an “institution.”
 - identify steps to be taken when People First / CACL become aware of an institution being built /not closed.

- The continued use of institutions be placed back on the agenda of the People First and CACL Annual General Meetings (AGMs) and Conferences, at the national, provincial, territorial and local levels. Resolutions be brought by both national organizations to their upcoming AGMs re: deinstitutionalization. Provincial/territorial/local members of People First and CACL be encouraged to pass similar resolutions.
- Immediately address the issue of new facilities being built in Nova Scotia, Yukon, and in other areas, and in the longer-term focus efforts on closing all existing facilities.
- People First discuss reactivating its Ribbon Campaign with its Executive.
- Required research be undertaken to more accurately identify:
 - ❑ How many people still live in institutions?
 - ❑ Where are they?
 - ❑ What is the situation in each province/territory?
- Create partnerships with other groups (Human Rights, other disability groups, professional associations, etc.).
- Educate / publicize the positive lessons we have learned in this country during the past 20 years. We know what constitutes a good planning process. We need to put these “lessons learned” together, and share this information widely.