



Community Living For All

Deinstitutionalization A Canadian Perspective

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WHY INSTITUTIONS?

- 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

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

BUT WE KNOW

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.

WE BELIEVE

The forced consignment of people with intellectual disabilities to institutions fundamentally violates their individual liberties. They haven't committed a crime, yet they are confined.

That this is not in accord with the basic values of our society and our Charter of Rights and Freedoms.

We recognize community living as a human rights issue and Canada has been regarded as a leader in this area.

But there's a huge gap between rhetoric and the reality. As a country we are still not fully meeting our commitment to people with intellectual disabilities.

CONTEXT FOR CHANGE

- Emergence of a strong parent's movement
- Emergence of a strong Self Advocate movement
- Both pointed out to governments the inappropriateness of institutional care

CONTEXT FOR CHANGE

- Unlike other jurisdictions we did not / could not rely on legal action to motivate change
- In Canada we have 2 levels of government – Federal and 10 Provincial / 3 Territorial
- Each Province /Territory responsible for its own policy
- We have had to create impetus for change by creating ‘political will’ among government and policy makers

CONTEXT

- Since the 1970s we have witnessed institutional closures in all of our provinces and territories
- In the 1980s our Federal government provided additional funds to enable institutional closures
- Yet institutions still remain open in 7 of our provinces
- Deinstitutionalization started – but not finished; and it is only in the last several years that we have again placed emphasis on this issue

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.”

CANADIAN GOALS

Benchmarks:

- By 2007 no admissions to large institutions
- By 2010 close all large institutions for people with intellectual disabilities
- By 2013 reduce by 50% those in inappropriate settings – like nursing homes
- By 2015 all supported living based on choice, self-determination, individualized funding
- By 2015 People with intellectual disabilities have access to the full range of housing options in the community

SUCCESSFUL STRATEGIES

- Families and self advocates working in collaboration and partnership
- Strong and consistent national leadership
- Forming partnerships with other human rights and community organizations
- Telling our stories of success and life in the community
- Knowing the arguments for institutions and being able to refute them with evidence and research
- Gaining political and bureaucratic support at all levels

SUCCESSFUL STRATEGIES

- Engaging in public awareness and education
- Framing our argument as one based on human rights and citizenship – not disability specific
- Using the media
- Presenting families and self advocates as the experts – not professionals
- Plan for all – not just those deemed ‘most ready’

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.

WE HAVE LEARNED

- Deinstitutionalization is as much about supporting people to continue to live in the community (i.e. prevention) as it is about closing facilities.
- 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.

WE HAVE LEARNED

At a systems level, the building blocks for deinstitutionalization include:

- Ongoing commitment to the goal and vision 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

WE KNOW THAT

People with disabilities are living in institutions not by choice, but rather due to a lack of efforts toward creating the necessary planning supports, and needed community supports and services, to enable their return to the community.

CONCLUSION

WE HAVE LEARNED

- That people do not need to be 'made ready' to live in the community
- That people continue to live in institutions because of flaws in our communities - not flaws in people
- That with appropriate support all persons with intellectual disabilities can live in community

OUR VISION

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