

A HOME OF OUR OWN

Policy Statement on Deinstitutionalization

Partners for Change

January, 2007

United Nations Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

Article 19

Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

INTRODUCTION

As stated in the preamble of the United Nations Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, which was passed in December of 2006, the Charter of the United Nations recognizes the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world, and that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind.

One of those inalienable rights is for persons with disabilities to live independently and to be included in the community. That means the right of everyone to a home of their own. Unfortunately, that right is being denied to many people with disabilities in Prince Edward Island. Those people are living in institutions, often against their will, they are not receiving adequate and in many cases, appropriate supports, and they are precluded from living as full and equal members of their - our- community. One of the most urgent needs and priorities facing people with disabilities is to develop practical and workable alternative to institutional living arrangements.

Partners for Change is advocating an end to institutional living arrangements for people with disabilities. That means, first of all, an immediate end to the institutionalization of people with disabilities. Secondly, it means beginning a process of de-institutionalization now, that is, enabling those who are now living in institutions to move to a home of their own in the community.

The purpose of the UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. One of the first steps to achieving that goal to ensure that all persons with disabilities have a home of their own.

Institutionalization in Prince Edward Island

For too long now, governments and society have paid lip service to the goal of community living. Despite many efforts over the years to support people with intellectual disabilities to live in the community, far too many continue to live in institutions. More alarmingly, the trend to place people in institutions appears to be growing.

A recent study carried out by PEI Citizen Advocacy on behalf of the provincial Association of Community Living found that there are 126 people with intellectual disabilities living in institutions across Prince Edward Island. These institutional settings range from manors, community care facilities, private nursing homes, and Sherwood Home and Hillsborough Hospital. These numbers do not include group homes specifically established for people with intellectual disabilities, many of which could also be categorized as institutions.

An institution has been defined by the Deinstitutionalization Task Force of the Canadian Association for Community Living and People First of Canada as “*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.*” Clearly, most of the facilities designed to serve the needs of people with an intellectual disability in Prince Edward Island are institutions.

As an aside, PEI People First has said that it regards any facility with more than four residents as an institution.

The study identified the fact that many people with intellectual disabilities are in inappropriate institutional settings, with inadequate services. Most of those are living in institutions designed for seniors, and they do not have the resources to address the needs of younger residents with intellectual disabilities. Of the 56 individuals with intellectual disabilities in community care facilities, 42 were not seniors. Of the seven provincially operated manors, 24 people were said to have an intellectual disability, and more than half of those were under the age of 60. There are six individuals with intellectual disabilities who are living in private nursing homes. At the time the study was carried out, they were under the age of 60 or were under that age at the time they were admitted.

The people who are institutionalized in these settings have identified a significant number of issues, including boredom, lack of support for any kind of activity, especially age-appropriate activity, lack of control over day-to-day decisions, limits on movement, excessive regimentation and lack of privacy. They also report little contact with people their own age, and being viewed in light of their medical needs rather than from a community living perspective. They share a lack of the possibility to develop personally, and a lack of belief in the community at large to help them lead more fulfilling lives.

Sherwood Home houses 13 residents, and another 24 people with intellectual disabilities are at Hillsborough Hospital. Although they offer some limited services and programs, these institutions are generally regarded as unacceptable places for people with intellectual disabilities in which to live - often for a lifetime.

A book published by PEI People First, called **On the Road to Freedom**, succinctly expresses the frustration of those who are consigned to live out the rest of their lives in an institutional setting. As one person put it, “I don’t have the words to speak it out but if I had them I would tell you. In there is not the right place. If I went back I’d be in for life. There are a lot of people who are in there for life. I’m better out.”

As another former resident of an institution recalled, “There wasn’t as much freedom. There were programs, and punishments if you acted up or if you were late. They would take your clothes away and you would have to wear pyjamas all day. Or you could get put in a side room. It was terrible.”

The problems associated with people living in institutions are only likely to intensify with an aging population. People with intellectual disabilities often require support throughout their lives, and as they age, they face increasing health care needs. As well, older parents of those with intellectual disabilities are less able to care for them. This has led to an increasing number of aging adults with intellectual disabilities being placed into manors and community care facilities, institutions which were not designed to serve them.

A survey of parents carried out under the PEI Community Inclusion Initiative found that the majority of families report that needs become more complex as their sons or daughters grow older. All of the parents are concerned about who will provide care to their sons or daughters after their own deaths. Less than ten percent had a plan in place.

With the lack of alternatives or options in the community, more and more people are expected to be institutionalized in the future unless some significant and meaningful changes take place.

Partners for Change is fundamentally opposed to the institutionalization of people with intellectual disabilities. That is why it is advocating that the admission of people with disabilities to institutions such as manors and community care facilities be ended immediately. There is a need to better plan to meet the needs and interests of individuals in the community. Only then can others be returned to their rightful place in society, with their rights and dignities protected and promoted.

Community Living

Community living, as a concept, needs to be fully recognized and understood if society is to achieve real progress towards greater inclusion of all its members. Efforts to support and assist people to leave institutions must be guided by the values and principles of community living. As a starting point, Partners for Change accepts the meaning of deinstitutionalization as stated by the Deinstitutionalization Task Force. According to the task force, deinstitutionalization means having:

- *the right to choose where one will live, and with who;*
- *services and 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); and*
- *services that meet all identified needs and are of high quality, portable and accessible.*

Partners for Change believes that there is an inherent right of people to live in the community and to be fully included in all aspects of the life of the community. The lives of people with intellectual disabilities must be characterized by a spirit of citizenship, in which they have their rights and freedoms respected and protected, and that they have the opportunity to meet their obligations as participating and contributing citizens. They must also have the opportunity to belong to families, friends, neighbourhoods, schools, places of work and all other aspects of the community. And they must have, like all other citizens, an active and decisive voice in decisions that affect their lives.

Giving expression to these values and principles is not an easy task. The stories of those who have left institutions and who are now living in the community is testament to the challenges they face. Creating the climate and the conditions for living in the community will require a great deal of hard work and discussion among government, service providers, families, friends, advocates and the people most affected.

Nevertheless Partners for Change is proposing the following goals to the provincial government.

Goal One - By 2007, the Government of Prince Edward Island will ensure that people with intellectual disabilities are no longer admitted to institutions which are publicly supported. These include, not only Hillsborough Hospital and Sherwood Home, but also all provincially-operated manors, subsidized community care facilities, and group homes with more than four residents.

Goal Two - By 2010, the provincial government will ensure that at least one-half of the people with intellectual disabilities who now live in the above-noted institutions be enabled to move out into the community.

Goal Three - By 2015, people with intellectual disabilities will have a home of their own in the community with the necessary supports and services to meet their needs.

By 2015, it is hoped that all those who are supported in the community will have access to the full range of housing options in the community. Along with this, they would be supported to make individual choices and their own decisions with individualized funding.

Next Steps

The benefits from living in the community, as opposed to institutions, are well-recognized. There are measurable improvements in the quality of living of people with disabilities, and the community itself is enriched as it becomes more inclusive. Community living can only be achieved when a real partnership exists between families, friends, advocates, governments and people with disabilities.

Partners for Change believes that the primary responsibility for care of people with intellectual disabilities rests with families. Resources which families cannot provide should next come from the community, with access to all the services, facilities and opportunities that are available to all members of society. Finally, it is the responsibility of government to ensure that all the necessary resources are provided which families and the community are unable to provide on their own.

Support for families and individuals must also come through changes in government policy. The recently announced initiative by the federal government to increase tax credits for families and individuals with disabilities is one such change. More planning supports might be available to parents and adults with disabilities. More can be done to provide flexible home care and respite supports. There is a need for more individualized community-based supports which provide a range of options, particularly for housing. Older adults with disabilities should be provided with the means of remaining in their own homes, and assuming ownership from deceased parents.

Governments and communities should undertake a comprehensive re-evaluation of their policies and programs to facilitate a shift from institutional models of service and program delivery to one which is determined by individuals themselves.

There have been some innovative approaches across the country in meeting the needs of people with intellectual disabilities. One of the most productive and positive of these approaches is based on the provision of individualized funding to people with disabilities who then seek out the supports and services they need and desire. In Prince Edward Island, the principles underlining the Disability Support Program appear to offer some degree of individualized funding. Obviously, a stronger and more comprehensive network of services and supports both within and outside government would enhance the ability of people with intellectual disabilities to live fuller and more satisfactory lives in the community.

This means more individualized planning, and more flexibility on the part of government to meet those needs which are identified through a planning process. That process should involve everyone who has an interest and stake in the lives of people with intellectual disabilities, and a means of identifying other resources which may be needed. Such person-centered planning should establish clear lines of accountability on the part of everyone involved.

This kind of an approach will have clear implications for the way government currently provides services for people with disabilities. At the same time, it will lead to a process for the development of more resources outside of government, in the community. Capacity building in the community will take time and resources, and governments and disability organizations must commit themselves to a process of community development.

This is not a new idea, but it is one that has never been fully accepted as the basis for policy in the field of disabilities. Partners for Change looks forward to continuing a dialogue with families, government and the community to complete the transformation from institutions to community living. Again, the first step is to immediately end the admission of people with intellectual disabilities to institutions and to begin the process of planning to meet their aspirations in the community to which they have an inalienable right of belonging. One of those inalienable rights is a home of their own.