

The Right Way

A GUIDE TO CLOSING INSTITUTIONS AND RECLAIMING A LIFE IN THE COMMUNITY
FOR PEOPLE WITH INTELLECTUAL DISABILITIES



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PEOPLE FIRST OF CANADA – CANADIAN ASSOCIATION FOR COMMUNITY LIVING
JOINT TASK FORCE ON DEINSTITUTIONALIZATION

PEOPLE
FIRST
OF CANADA



PERSONNES
D'ABORD
DU CANADA



50 years

Canadian
Association for
Community Living

Diversity includes.

How an institution is closed is just as important as the imperative that all institutions must be closed.

Each person takes their rightful place in their own home in the community — not as a “resident” or “client” — but as a full citizen and a valued, included community member.

Preface

This booklet is a guide for community and government leaders involved in planning the closure of institutions for persons with intellectual disabilities and the creation of supports to enable individuals to move from these institutions to their own homes in the community.

Beginning with background information about institutions, community living, public policy and human rights, *The Right Way* presents principles and key elements for planning the closure of an institution based on lessons learned in Canada and elsewhere over the past 30 years. Our title, *The Right Way*, has been carefully chosen — not to suggest a single, correct approach, but as a bold statement emphasizing that *how* an institution is closed is just as important as the imperative that all institutions must be closed.

This document was prepared by the People First of Canada (PFC) — Canadian Association for Community Living (CACL) Joint Task Force on Deinstitutionalization (hereafter referred to as the “Task Force” or “Joint Task Force”). PFC and CACL established the Joint Task Force:

“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.”

The Task Force includes survivors of life in Canadian institutions as well as community living advocates from across the country. The Task Force promotes supported living options for all people with intellectual disabilities, closure of the remaining institutions for people with intellectual disabilities in Canada and the prevention of new institutions being created in any form.

Over the past 30 years, many provinces in Canada have closed all of their large institutions for people with intellectual disabilities and created necessary supports in the community. These accomplishments, the lessons learned and mistakes made, prompted discussions by Task Force members about the importance of sharing information with leaders in provinces which have yet to complete the process of closing institutions. Those discussions led to the creation of this guide.

Our goal in presenting this guide is to assist community and government leaders to close institutions — the right way — so that the best possible outcomes are achieved for everyone involved. This includes individuals, families, communities, employees and many others. Most importantly, *The Right Way* is intended to promote achievement of the best possible outcomes for people with intellectual disabilities, enabling each person to take their rightful place in their own home in the community — not as a “resident” or “client” — but as a full citizen and a valued, included community member.

Introduction

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Before exploring the key elements of an institutional closure plan, it is helpful to review background information about institutions and community living including relevant history, human rights, research, public policy and guiding principles.

What is an Institution?

Individuals with disabilities provide an essential perspective:

“Institutions deny you a life — they take away your ability to know and connect to your family and your community — they 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.”

(Patrick Worth, Founding Chair, Joint Task Force)

Sociologist Erving Goffman coined the term “total institution” to refer to:

“a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed formally administered round of life.”

(p.11, Goffman, 1968)

Goffman identified prisons and institutions for people with disabilities as examples of “total institutions”. Survivors of Canadian institutions frequently make comparisons with jails:

“It was just like a jail. You couldn’t do nothing. You couldn’t make conversation like I’m doin’ now....I wouldn’t call it Woodlands, I’d call it a jail...If you are hard to handle, they put you on one ward... I didn’t go to school. I don’t know why they call it a school.”

(Marianne Crowley, p.110-111, Melberg Schwier, 1990)

PFC-CACL Joint Task Force Definition of an Institution

The Joint Task Force developed the following statement to define an institution (this definition has since been adopted by disability rights organizations around the world):

An institution is a place where people are not permitted to dream.

An institution is not defined merely by its size.

From the inception of institutions to the present, insiders, observers, public inquiries and courts have cited abuse, neglect and isolation of residents in institutions.

“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 the day to day decisions. An institution is not defined merely by its size.”

(PFC-CACL Joint Task Force on Deinstitutionalization, 2002)

In addition to those institutions designated specifically for persons with intellectual disabilities, it is known that thousands of individuals throughout Canada are inappropriately living in other facilities such as nursing homes, seniors' homes, personal care homes, long term care facilities, large group homes, and rehabilitation and residential centres. In Nova Scotia, for example, there are no institutions designated specifically for persons with intellectual disabilities, yet approximately 650 people with disabilities (the majority of whom have intellectual disabilities) are housed in such facilities. While the focus of this guide is the closure of institutions for persons with intellectual disabilities, there is an equal imperative to assist people with intellectual disabilities living in these other institutional facilities to also return to community. The elements presented in this guide are equally applicable for use in these situations.

History of Institutions

A review of the history of institutions housing people with intellectual disabilities tells us:

- Institutions have existed for centuries, dating at least as far back as the 13th century.
- Across North America, institutions began to be established in the mid-1800s.
- Initially, institutions were foreseen as a modern, enlightened approach.
- From the inception of institutions to the present, insiders, observers, public inquiries and courts have cited abuse, neglect and isolation of residents in institutions.
- In the 20th century, sterilization, medical experimentation and other abuses occurred.
- Hundreds of institutions were built across the continent from the 1830s to 1970s with the first Canadian institutions established in New Brunswick, Ontario and Quebec.
- For more than a century, few alternatives to institutionalization were available to families and tens of thousands of Canadians lived and died in these facilities.
- In the 1950s, families and activists began to demand the closure of institutions and the creation of community-based services.
- In the 1960s and 1970s renewed criticisms and court judgements condemned North American institutions as inhumane, harmful and a violation of human rights.

- By the early 1970s, provincial governments in Canada began to call for and plan the closure of institutions and the provision of community based supports.
- In 1986, 10,000 Canadians with intellectual disabilities were living in 31 large institutions (100 or more beds) across the country.
- By 2009, Newfoundland and Labrador, New Brunswick, British Columbia and Ontario had closed all of their large institutions for people with intellectual disabilities.
- As of 2010, approximately 900 Canadians are still institutionalized in three large (100 or more beds) provincial institutions designated for people with intellectual disabilities in Manitoba, Saskatchewan and Alberta.
- Thousands of Canadians with intellectual disabilities continue to be institutionalized in inappropriate facilities such as nursing/seniors homes, personal care homes and other long term-care facilities.

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Human Rights, Research Evidence and Public Policy

Human Rights

Originally, institutions were created with the intention of providing quality care and safe environments for people with disabilities. Today it is recognized almost universally, that institutions are unnecessary and harmful and that life in the community is a fundamental human right — a right now protected by the UN Convention on the Rights of Persons with Disabilities!

Convention on the Rights of Persons with Disabilities

Article 19 — Living independently and being included in the community

States Parties to the present 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:

- 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;**
- 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;**
- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.**

Institutions are unnecessary and harmful and life in the community is a fundamental human right.

Research evidence consistently demonstrates the benefits of community living and the harmful effects of institutionalization.

All provincial and territorial governments in Canada have made policy commitments in support of community living.

Article 19 of the Convention states that people with disabilities must “*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*”. On March 11, 2010, with the support of all provinces and territories, the Government of Canada ratified the UN Convention on the Rights of Persons with Disabilities at United Nations headquarters in New York City.

Closing institutions and helping people move to their own homes in the community is something community living advocates have argued is simply the right thing to do, based on the dignity and respect that all people deserve. Under the Convention, this is now a legal obligation.

Research Evidence

From the earliest to most recent times, arguments have been advanced to justify institutionalizing people. Typically, these arguments included notions that institutions could provide better care or ensure better health, that people would be happier “with their own kind”, or that people with “severe” disabilities, complex health or behavioural issues could not be supported in community.

All of these arguments have been dispelled as myths — by the example of people with disabilities themselves and also through research studies. Research evidence consistently demonstrates the benefits of community living and the harmful effects of institutionalization. Studies conducted over the past 50 years in North America have documented the following outcomes for people with disabilities in the community compared to the institution life:

- Maintained or improved health and health care.
- Increased independence and adaptive skills.
- Decreases in/elimination of challenging behaviour.
- Increased family involvement and support (families overwhelmingly support community living following institution closures, even if they had previously opposed it).
- Lower costs for community based supports compared to institutions.
- Successful transitions to community by individuals with the most complex needs (people with severe disability, challenging behaviour, medical issues, or advanced age).

Public Policy

Public policy in Canada has evolved considerably since the early 1970s, when provincial governments first began to talk seriously about closing institutions. In 1971, Saskatchewan became the first province to close a large institution with the closure of Weyburn Mental Hospital. 1973 saw the release of a report by Robert Welch, Secretary of Social Development called *Community Living for the Mentally Retarded in Ontario: A New Policy Focus*. In what may have been the first official use of the now familiar term *community living*, this paper called for the creation of appropriate homes in the community and the establishment of a

coordinating mechanism to ensure that a wide range of services be made available to people with intellectual disabilities in the community.

Despite these early discussions and promising policy developments, the transition to community living proceeded slowly until the 1980s. Today, while pockets of resistance still exist, the policy debate about whether it is appropriate to place people with disabilities in institutions is largely resolved in Canada and throughout the world (Mansell and Beadle-Brown, 2010). The focus and energies of community and government leaders have now shifted to the challenge of how best to accomplish the dual processes of closing institutions and creating supports that are truly individualized — supports that respect each person’s rights, dignity, needs and aspirations.

All provincial and territorial governments in Canada have made policy commitments in support of community living. In Newfoundland, British Columbia, New Brunswick and Ontario, all institutions for people with intellectual disabilities are now closed and politicians have heralded new policy directions supporting community living:

“More than a quarter century ago, the government of Newfoundland and Labrador made a decision that institutions would no longer play a role in the lives of persons with intellectual disabilities.”

(The Honourable Shawn Skinner, Minister Responsible for Persons with Disabilities for the Province of Newfoundland and Labrador, 2008)

“Today it is understood that society as a whole benefits when those with disabilities have recognizable rights. These include the right to participate in their own home communities, to live in the same neighbourhoods as their friends and family...”

(The Honourable Claude Richmond, British Columbia Minister of Employment and Income Assistance, 2008)

“Over the last three decades, New Brunswick has held firm to the position that all individuals have a right of citizenship to reside in their local communities with dignity, respect and receive the supportive services they require.”

(The Honourable Mary Schryer, Minister of Family and Community Services for the Province of New Brunswick, 2008)

“...with these final closures, we have officially shut the door on an outdated philosophy... We have proved that the strengths of people with a developmental disability overcome any challenges...with the right supports — these people can live with the independence and choice we all enjoy.”

(Honourable Madeline Meilleur, Ontario Minister of Community and Social Services, 2009)

Public policy in these provinces has clearly shifted in favour of community living. Provincial leaders in other Canadian provinces have also expressed support for the rights of people with intellectual disabilities to live in the community. Continued policy development, leadership and vigilance will be needed to ensure that people are enabled to live in real homes in the community and to prevent the

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re-creation of institutions in any form. The current challenge is to ensure that this policy direction is adopted by the entire country and translated universally into practice.

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 that person's 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 to assist in decision making (supported decision making);
6. Services that meet all of their needs and are of high quality, portable and accessible.

Key Elements of Successful Closure Plans

A number of key elements have emerged from deinstitutionalization processes in Canada and elsewhere over the past 25 years. These “lessons learned” are presented here as a set of recommendations for community leaders seeking to create *the right way* to close an institution and create real homes in the community for people with intellectual disabilities:

1. INVOLVE CHAMPIONS FOR COMMUNITY LIVING

The Canadian experience illustrates that the decision to close an institution and embrace community living requires vision, passion, leadership — and champions. These champions have come from every sector of society — from the volunteer sector, advocacy organizations, from community living agencies; from inside the institutions, from within government and political parties. Family members often take the lead role in demanding both institution closures and community supports. People with disabilities are also on the forefront, demanding that their fellow citizens be freed from institutions and supported to live good lives in their communities.

In 1982, Newfoundland and Labrador became the first province to implement a policy of full deinstitutionalization, with Minister T. V. Hickey announcing that “institutions will no longer play a role in the lives of persons with developmental disabilities”. Within six years, the province closed its two institutions for persons with intellectual disabilities.

In British Columbia, Jo Dickey, whose son lived at Woodlands institution, led a group of parents demanding the closure of Woodlands and the planning of community supports for all residents. Jo and her group were uncompromising and the province soon committed to closure. Within a few years, as President of CACL, Jo would put deinstitutionalization on the national agenda.

In Ontario, Minister Sandra Pupatello made the historic announcement that the government would close all remaining institutions in four years! That decision was followed up with determination by her successor, Minister Madeline Meilleur who completed the process in 2009.

In 2007, members of People First of Canada travelled across the Prairies to raise awareness about people still living in institutions. This journey is chronicled in the NFB documentary, *The Freedom Tour*, in which David Weremy, Bill Hogarth,

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The closure of an institution has far more to do with planning for each individual than it has to do with emptying out and closing institutional facilities.

Planning must be person-centred and individualized.

Planning should be seen as ongoing and not a one-time process.

Tedda Kaminski and other self advocates talk about their experiences in Canada's three remaining large provincial institutions for persons with intellectual disabilities (Manitoba Development Centre in Portage La Prairie, ValleyView Centre in Moose Jaw and Michener Centre in Red Deer) and their concerns for the nearly 900 people still residing in those facilities. These champions call upon leaders across the country to rise to the challenge of closing these institutions and bringing everyone home!

Champions will emerge from different sectors in each jurisdiction. It is crucial to engage a broad array of champions and allies to forge a united approach to achieving institutional closures.

2. ENSURE THAT THE NEEDS AND PREFERENCES OF THE PERSON COME FIRST

The closure of an institution has far more to do with planning for each individual than it has to do with emptying out and closing institutional facilities. It is primarily a process of creating responsive, individualized supports and services that will enable each person to live in his or her own home, to engage in meaningful activity in the community and make decisions about his or her own life.

Some institutional closures have been characterized by a “cookie cutter” approach, in which service models, such as group homes, are imposed, with individuals being “placed” according to the perceived needs of a group. While this approach may be appealing and may appear to be efficient in the short term, the resulting living arrangements usually fail to meet the needs of individuals and invariably lead to problems (institutional service delivery, interpersonal conflicts, etc.) and inefficiencies (multiple moves, additional professional interventions, etc.). This approach may also violate the person's rights under Article 19 of the UN Convention.

Each individual must be empowered to choose where and with whom to live and the resulting living arrangement must truly be that person's home — not a facility, not a workplace and not a place where arbitrary rules or the needs of staff or others come first.

Planning must be person-centred and individualized. An independent facilitator or an ally of the person for whom planning is done will be better situated to facilitate the plan than a service provider or funding body representative who may be constrained by policies, pre-determined service models or other influences that interfere with putting the person first. It must also be understood that as with any person, an individual's preferences and needs may change once they are in the community. Planning should be seen as ongoing and not a one-time process.

Finally, funding should be individualized and attached to the person so that if he or she needs to move, they will be free to do so and not trapped in a block-funded, agency-controlled model.

3. RESPECT THE EXPERIENCES AND ROLES OF FAMILIES

The perspectives of families must always be taken into account when initiating planning for an individual to move to his or her own home in the community. In the past, families were routinely advised that institutional placement was best for their son or daughter and for the family as a whole. In some cases, families were told their child's health was "fragile" or that they would only live for a short time. Some health care professionals told families to forget about their child and move on with their lives.

It should be expected then, that some families will be distrustful and feel a sense of betrayal when professionals now tell them that institutions are no longer needed or that they were never appropriate places for people to live. Some families may fear that they will become solely responsible for their son or daughter's care or that their loved one may be "dumped" into an inferior living situation or even be at risk of homelessness.

For these and many other reasons, families should be informed and involved from the outset. Other than in the exceptional situation where the individual does not have any immediate family or does not want his or her family involved, families should have a central role in developing individualized plans with their family member. Families will often be the best source of information about the person and will often form the nucleus of the person's support network in the community.

Families who have already been through the experience of an institutional closure and the planning of successful transitions to life in the community should be invited to play a key role in providing initial information and support to families.

Planning may also be enhanced by designating someone with excellent family support skills to work with families to ensure that they are provided with timely and useful information and support throughout the process.

4. FACILITATE PERSON CENTRED PLANS AND CREATE A REAL HOME FOR EACH PERSON

Individuals, families, communities and agencies in provinces which have closed their institutions have demonstrated that a wide array of supports and services can be accessed or created to meet the full range of needs of citizens with intellectual disabilities.

Individualized, person-centred planning, facilitated by an ally of the person or an independent facilitator, will help ensure that each person moves to his or her own home in the community. Like anyone else, some individuals will choose to live on their own with supports while others may choose to live with others for practical or personal reasons.

It must be emphasized and re-emphasized that services must be based on the individual needs and preferences of the person being supported. Pre-determined

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Services must be based on the individual needs and preferences of the person being supported.

On-going monitoring will be needed to ensure that policy supporting community living is translated into quality individualized supports in the community for all individuals with intellectual disabilities.

Safeguards and monitoring plans should also be embedded within the individualized plans for each person moving to the community.

service models and living arrangements based on the perceived needs of a group simply replicate the institutional model on a smaller scale. Such models are often presented as “innovative”, but this is misleading. Innovation, per se, is not the goal — the goal is to support the individual in ways that meet his or her needs and allow him or her to live in a real home, to participate meaningfully in community life, to make real choices and have his or her rights and wishes respected.

Engaging in respectful, person-centred planning will maximize the potential for achieving positive personal outcomes. This does not mean that there will be no barriers or challenges encountered as specific supports and housing choices are being sought. For example, some communities will have shortages of specialized services, there may be insufficient accessible housing available in some communities, and all communities will go through periods when it is difficult to recruit skilled support staff. These issues are to be anticipated and must be addressed in the context of the overall closure plan.

The creative use of resources and protocols to address potential gaps or conflicts in providing community living supports should be addressed within and across all relevant policy areas of government including employment, education, health and social services. On-going monitoring will be needed to ensure that policy supporting community living is translated into quality individualized supports in the community for all individuals with intellectual disabilities.

5. CREATE QUALITY SUPPORTS, SERVICES AND SAFEGUARDS

For the most part, the supports needed by individuals residing in institutions are already available in the community and can be enhanced as part of the deinstitutionalization process. Resources previously allocated to the institutions for such things as housing, personal care, dental care, equipment, etc., are re-allocated to communities to ensure adequate capacity to support everyone in the community.

The need for increased capacity in communities can be identified in a systematic and timely way, so that planning can occur and supports are in place when individuals make the move to their homes in the community. Some transitional funding may be required to develop or expand community resources while the institution is still operating. This transitional funding should be time targeted and when all people have moved, the resources once tied to the institution will all have been re-allocated to support people living in the community.

Policies and strategies for monitoring the quality of services and establishing safeguards must be built into the closure process from the earliest planning stages. Safeguards and monitoring plans should also be embedded within the individualized plans for each person moving to the community.

A variety of methods have been adopted to measure the quality of community living supports and services and to evaluate the effectiveness of safeguards. Some approaches involve the measurement of minimum standards of quality, while other approaches take a more holistic approach that looks at both formal and

informal approaches to evaluating services and promoting safeguards. Leaders in jurisdictions which have closed their institutions should be consulted and a careful plan should be adopted to incorporate effective approaches and avoid ineffective ones.

Given that the primary consideration is the individual who is moving from the institution to the community, the primary emphasis of evaluation should be on the outcomes for and satisfaction of each individual. While it is generally agreed that people will be safer in the community than in institutional settings, people with intellectual disabilities still have vulnerabilities and less power to protect themselves than the average person, therefore, creating safeguards is essential.

One of the most important and obvious outcomes to consider is the extent to which the wishes, preferences and needs of each individual are being addressed and the extent to which the resulting living arrangement is a real home for the person. There may be some objective measures of these outcomes, but the individual and his or her support network will clearly be in the best position to judge whether he or she feels their home is their own, whether they are able to make real choices or feel included in their community and whether he or she feels that his or her rights and wishes are being respected.

A discussion paper published in 2007 by Community Living British Columbia (CLBC) discusses the need for “multi-level safeguards” including the roles of families, networks and community and both formal and informal safeguards. “Intentional safeguards” are things that are planned for the specific purpose of reducing the person’s vulnerability. The CLBC paper, entitled *Responding To Vulnerability: A Discussion Paper About Safeguards & People With Developmental Disability* also discusses the importance of unplanned safeguards, like having friends and neighbours who know you and who take action when concerns arise. This paper can be found at this link:

<http://www.gobaci.com/resources/Safeguards%20Discussion%20Paper.pdf>

It is advisable that careful planning occur to ensure that formal steps are taken to monitor outcomes and implement safeguards while also ensuring that opportunities are taken to create the kinds of informal safeguards that may help to keep people safe.

Certainly, it may also be useful to evaluate the deinstitutionalization process itself — the results of such an evaluation may indicate what went well and what might have been done differently. This information may be useful for government and community leaders involved in the closure and also for leaders planning institutional closures in other jurisdictions.

6. RECRUIT AND DEVELOP QUALIFIED SUPPORT STAFF

Government and community leaders will need to develop plans to address staffing issues related to both the creation of person-centred community services and the closure of the institution.

One of the most important factors in the success of community living arrangements is the availability of skilled, knowledgeable employees to provide

The primary emphasis of evaluation should be on the outcomes for and satisfaction of each individual.

Intentional safeguards are things that are planned for the specific purpose of reducing the person’s vulnerability.

One of the most important factors in the success of community living arrangements is the availability of skilled, knowledgeable employees to provide the individualized supports needed.

It is essential to involve employees and unions early in the process — not to negotiate the decision to close the institution — but to demonstrate respect for the impact of the closure on institution staff and to offer opportunities to work in partnership.

the individualized supports needed by individuals with intellectual disabilities in their homes and communities. While qualified staff may be readily available in some communities, virtually all communities go through periods where it is difficult to find and retain qualified support staff. This may be especially true in places where community support staff are not well compensated or where there is stiff competition from other employers who are able to offer better pay or other incentives.

The announcement that an institution will close may be met with opposition from unions and employee associations representing institution staff. Employees and their representatives will have concerns about job disruptions and losses. Unions have sometimes responded by defending the institution and questioning the capacity of communities to provide the level of care provided in the institution. It should be remembered that unions have strong roots in the social justice movement. Just as the 1948 Universal Declaration of Human Rights explicitly supported the right to form and join trade unions, the new UN Convention on the Rights of Persons with Disabilities now supports everyone's right to be free to live in the community. Some unions have social justice committees which may become involved in order to highlight the human rights issues inherent in the community living and deinstitutionalization movements.

For all of these reasons, it is essential to involve employees and unions early in the process — not to negotiate the decision to close the institution — but to demonstrate respect for the impact of the closure on institution staff and to offer opportunities to work in partnership to make the transition as positive and painless as possible for all concerned. In most unionized environments, collective agreements will address issues of staff re-deployment. Such procedures are designed to ensure an appropriate job match for employees and the matching process will need to ensure that community living values and skills are paramount in re-deployment decisions.

Many former institution staff will thrive in community-based environments, while others may have difficulty making the transition. In jurisdictions which have closed their institutions, strategies for accommodating existing institutional staff have included re-deployment to community agencies or other provincial government work and early retirement.

Training opportunities may be enhanced for both institution staff and prospective employees in the communities to which individuals plan to move. By re-deploying staff who are well suited to work in new capacities within community, resistance to the closure process may well be reduced. Indeed, allies can be found among institution staff who know individuals well and may be interested in making the transition to the community with them.

Government departments involved in employment, education and a range of other areas will need to work with the institution, associations for community living, local colleges and municipalities to recruit and develop qualified staff in the communities where former institution residents choose to live. Person-centred thinking and planning should result in the early identification of destination communities. With this knowledge, government and community efforts can focus on ensuring adequate preparation and resource allocation in those communities.

7. ESTABLISH COMMUNITY PARTNERSHIPS

The successful closure of an institution depends on sound collaborative working partnerships between individuals, families, government and community organizations and any number of diverse allies.

At the local and provincial level, the involvement of advocacy organizations such as People First and Associations for Community Living is essential. The national organizations of these bodies may also be able to lend a hand. People with intellectual disabilities and their supporters are uniquely situated to speak with knowledge and credibility about the rights of people with disabilities to be free of institutions and to live in their own homes in their communities.

Alliances should be nurtured with family support organizations, local advocacy groups, social justice advocates, service groups, unions, business leaders and other possible allies. As noted, champions may come from any sector or perspective, therefore any individual, organization or business may emerge as a critically important ally.

Careful attention should be given to developing and maintaining positive relationships among the (soon-to-be) former residents and their support networks, personnel from the institution and agencies and associations that may be involved in supporting people to live in the community. These partners must work together from the planning stages to the transition to the community to ensure that service planning is truly person-centred and individualized, that the rights and choices of each individual remain paramount and that adequate, appropriate, personalized community supports and services are planned and secured.

The assistance and support of a broad and diverse array of individuals and organizations will be critical in ensuring a clear and informed message that the closure of institutions has community support and is in the best interests of individuals with disabilities and the community as a whole. These partnerships will also enable government to respond to opposition in a non-partisan way.

8. ESTABLISH A CLEAR PLAN AND TIME FRAME FOR CLOSING THE INSTITUTION

Government and community leaders must make a bold commitment and present a clear plan to close the institution. *The Right Way* is not a guide for down-sizing institutions for people with intellectual disabilities, for moving only some people out of the institution or for creating mini-institutions to replace larger ones.

A clear public policy supporting community living should be established to provide the foundation for community living rights and a clear message that institutional models will no longer be supported by public policy or funds.

Government and community leaders must share a clear, unequivocal, public commitment that the institution will be closed, that resources will be allocated to the community and that planning will ensure that each person residing in the institution will be supported to move to his or her own home in the community. Announcing the intent to close the institution is a critical step.

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Partners must work together from the planning stages to the transition to the community to ensure that service planning is truly person-centred and individualized, and that the rights and choices of each individual remain paramount.

Government and community leaders must share a clear, unequivocal, public commitment that the institution will be closed.

A clear time frame for completing the process is essential.

Government and community leaders must be well prepared with clear information about what is planned and why the decision is in everyone's best interests.

Learning from the experiences of jurisdictions which have gone through the process is vitally important at this stage. Government and community leaders should consult with these colleagues as well as with local, regional and provincial partners to develop a comprehensive closure plan and a strategy for communicating the decision and the process to the public.

Many Canadian jurisdictions have begun by making the fundamental decision to stop all admissions to the institution. This ensures that a community based response becomes mandatory. Renovations within an institution should be undertaken only for health and safety reasons in the interim until the facility is fully closed.

A clear time frame for completing the process is also essential. Although plans to close Ontario's institutions were initially proposed as early as 1971, it was not until 2005 that a clear plan and timeline for closing all institutions (March 31, 2009) was announced. This commitment led to real action that saw almost 2,000 people successfully move to the community in four years.

Prior to announcing the closure, basic steps and a clear time frame should be established for the entire process.

9. COMMUNICATE THE ANNOUNCEMENT CLEARLY AND EFFECTIVELY

Once the decision has been made to close the institution, careful consideration must be given to how the decision is announced and how messages related to the closure and plans for creating individualized supports for people in the community will be conveyed — both initially and throughout the process.

It should be expected that there will be at least some opposition to the closure. Opposition may be mild or extreme and may emanate from a number of sources or perspectives. Typically, opposition has come from family members concerned that their family members cannot be supported adequately in the community and/or from unions or community leaders concerned about job losses and economic impacts on communities where the institution operates.

In anticipation of these and other concerns, government and community leaders must be well prepared with clear information about what is planned and why the decision is in everyone's best interests, especially the interests and rights of citizens with intellectual disabilities.

Background information and fact sheets dealing with anticipated questions and concerns about institution closures should be developed and refined to address local issues. Media releases and strategies for promoting the plan and dealing with opposition should be crafted to ensure a focus on the rights of people with disabilities and respectful consideration of other interests.

10. CAREFULLY COORDINATE/SUPPORT EACH PERSON'S TRANSITION TO THE COMMUNITY

Like most aspects of planning for the closure of an institution, the planning of each person's transition to the community is highly individualized. Each person's individualized plan will have identified such basic things as where and with whom the person will live, what kinds of supports and services they will need, how these will be provided, what kinds of activities the person may engage in at home or in the community as well as details such as how their home will be decorated.

For some individuals (and their support networks), the physical move to the community may need to be carefully orchestrated. Some people may require a series of visits to their destination community, neighbourhood and home, while for others, these types of visits may be of a more practical nature (to observe and direct the planning or decorating of their home). Many individuals have made quick transitions to living in their new home with little to no negative impact. Others may require a more gradual change from the old environment to the new one.

The people who know the person well will be in the best position to help plan the transition and any intermediate steps, if needed. Whatever process is decided upon, the transition period is an extension of the individualized plan and must be approached with care and attention to the unique needs of the individual.

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SECTION

3

People with intellectual disabilities are best supported in real homes in the community.

Since 1986, more than 90% of the country's institutions for people with intellectual disabilities have closed.

Conclusion

The *Right Way* has been presented by the PFC-CACL Joint Task Force On Deinstitutionalization as a guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities.

We have discussed how lessons from the history of institutions, from research and from the lives of people with intellectual disabilities have led to important shifts in our beliefs and values, in our recognition of human rights and ultimately, in public policy and in the ways in which people with intellectual disabilities are supported in our communities.

We have outlined 10 key recommendations that have emerged as critical to creating real homes and planning the closure of an institution. To summarize, these are:

1. Involve champions for community living
2. Ensure that the needs and preferences of the person come first
3. Respect the experiences and roles of families
4. Facilitate person centred plans and create a real home for each person
5. Create quality supports, services and safeguards
6. Recruit and develop qualified support staff
7. Establish community partnerships
8. Establish a clear plan and time frame for closing the institution
9. Communicate the announcement clearly and effectively
10. Carefully coordinate/support each person's transition to the community

Today, most Canadians know that people with intellectual disabilities are best supported in real homes in the community. The majority of provinces which operated institutions for people with intellectual disabilities have now closed these facilities and embrace community living for all. Since 1986, more than 90% of the country's institutions for people with intellectual disabilities have closed and the number of individuals living in these large institutions (100 or more beds) has decreased from 10,000 to approximately 900.

While this decrease represents a significant achievement, the challenge still before us is to ensure that community living becomes a reality for every person with an intellectual disability in Canada — for those individuals in large institutions, and for all Canadians housed in inappropriate facilities of any kind. This is no longer just a plea from the community living movement — it is a basic human right which provincial and territorial governments are obliged to protect. Under the UN Convention, Canadians with intellectual disabilities can no longer be required to live in institutions.

With the closure of its remaining institutions in March 2009, Ontario demonstrated that it was possible to complete person-centred planning and the transition of 2,000 people to the community in less than four years. This means that it is reasonable to expect that the 900 people who reside in Canada's three remaining provincial institutions for people with intellectual disabilities could be supported through person-centred planning to move to their own homes in their communities within two to three years.

The achievement of community living for all Canadians will require courage, leadership and commitment from government and community leaders across the country. Even with the closure of Canada's large institutions, on-going leadership and vigilance will be needed to ensure that new institutional models are rejected when proposed and that existing community services are monitored and modified as needed to ensure that every person has a real home in the community.

The closure of Canada's institutions for people with intellectual disabilities will be an important achievement. It will also be a symbol of our maturity as a country and it will mark our passage from a long history of dehumanization and exclusion to a new era of citizenship and inclusion.

Most importantly, we must do it *the right way* — by planning carefully with each person and his or her supporters to ensure that he or she has a real home in the community and the opportunity to contribute, participate and be included as a full citizen and community member.

Under the UN Convention, Canadians with intellectual disabilities can no longer be required to live in institutions.

The achievement of community living for all Canadians will require courage, leadership and commitment from government and community leaders across the country.

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