

# institution watch

PEOPLE  
FIRST  
OF CANADA



PERSONNES  
D'ABORD  
DU CANADA



50 years

Canadian  
Association for  
Community Living

Diversity includes.

Fall 2012 / Volume 6, No. 4

Monitoring the  
progress toward  
a vision of full  
community living  
for *all* persons  
with intellectual  
disabilities.

This is a newsletter  
written and produced  
by the People First of  
Canada-CACL Joint  
Task Force on the  
Right to Live in  
Community.  
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*"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."*

## FALL 2012

### MESSAGE FROM THE TASK FORCE

Laurie Larson and Shane Haddad, Co-chairs

The right to live in community, the ability to choose where and with whom we live, and the right to make our own decisions. These are not extraordinary expectations. Indeed for the majority of Canadians, these are so basic to our citizenship that most of us take them for granted. Yet for many people with intellectual disabilities, these basic elements of citizenship remain elusive.

All too often our efforts to assist people to live meaningful lives in community become more about programs and services rather than the outcomes these supports are supposed to enable. We need to remember that programs and services are intended to be tools to assist people with intellectual disabilities achieve inclusive lives in community, not outcomes to be sought. What is important is not the number of programs, services or options we create but rather do these in meaningful ways increase the extent to which people with intellectual disabilities are supported to exercise control over their lives, to make decisions for themselves, and to choose where and with whom to live.

We must see past the programs and services and focus instead on the inherent values behind these programs and services – increased choice, control, participation, and decision-making. We need to recognize that existing programs and services do not always adhere to these values. We need to recognize that programs do not have any value in themselves; that their value is defined only to the extent to which they assist people to create inclusive lives in community. If they do not, then we must reevaluate how we are supporting people. Let's begin to evaluate the effectiveness of our services – not on the basis of cost effectiveness, or funding levels or staffing levels – but instead by asking if these programs and services help people live inclusive lives in community? It is really the only question that matters!

## GUEST EDITORIAL



### REFLECTIONS ON AN INSTITUTION

By David Weremy

I lived in the Manitoba Developmental Centre, on and off, for 19 years. I did not ask to go there. I never liked it there. Life was rough. Staff would beat up the boys. Boys were rough with each other. You couldn't say anything or you would get in trouble. I often worry that they may take me back now, if I speak up. If you did something wrong, they took you back. If the Doctor said you had to live there, you had no choice. I would get out and if I did something wrong, they would take me back.

Give the boys their freedom, no more locking them up. I want them to have more freedom.

We tried; we talked to the government about Human Rights. They said no though, they don't want to close it down. I don't like it. I think they should close it down! Get it the heck out of there! That's the wrong thing they are doing. What they say is no good; people should be free. They did it in Ontario; they did it in Newfoundland. Why not in Manitoba?

I think they should talk about it more. I think they should talk to the boys who are still living there. I think they should take the building and sell it. Put a big for sale sign on it. Turn it into a hotel. Tell the boys they can be free — that they can have a life like me. You can do anything you want to do. Nobody stops you doing nothing. But you can't break the law.

Give the boys their freedom! I have my freedom and will not give it up. I am going to do all I can to make sure other people who are locked up in institutions like MDC get their freedom too.

## ONTARIO COMPLETES STUDY OF INSTITUTION CLOSURES

### INTRODUCTION

In 2009 the last three large institutions for people with an intellectual disability in Ontario were closed and the 941 remaining residents moved to the community. The government contracted Brock University to conduct The Facilities Initiative Study which looked at how the closures were handled and how communities welcomed people. Within the larger study were four specific investigations: Family and Agency Survey; Focus Group and Interview Study; Intensive Case Studies; and a Quasi Longitudinal Study.



It is anticipated the final report of the Study will be released in the fall, but Dorothy Griffiths and Frances Owen, two of the researchers, presented findings of the Family and Agency Survey and the Focus Group and Interview Study at the IASSID (International Association for the Scientific Study of Intellectual Disability) Conference in Halifax in July of this year. The remainder of this article presents some of the highlights of their presentation, as prepared by Laurie Larson and Rick Tutt.

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## **FAMILY AND AGENCY SURVEY**

### **Family thoughts**

The researchers surveyed 61 families who agreed to participate in this study. For the majority of participating families the transition for their family member to the community was easier than expected and most families expressed an overwhelming satisfaction with the placement and support.

The indicators that were rated and scored as 'satisfied' included: the present placement; staff support; location of the living arrangement and proximity to family; layout of the home; quality and amount of and access to medical supports.

Following the transition to community more participating families reported that they visit, call or entertain visits from their relative. A small number of the families reported less contact. The general rating by the participating families regarding the quality of life for their family member in the community as excellent or good was 87% although 10% indicated the situation was poor or needed improvement.

### **Agency feedback**

The researchers surveyed community agencies, representing 114 people who had moved from the institutions. Of the people who moved from the institutions 92% moved to group homes and of these people 31% lived in group homes of less than 3 people, 59% lived in group homes of 4-7 people and 10% lived in group homes of 13 or more people. The researchers commented that many of the homes exceeded current sizes recommended in literature.

In terms of how people adjusted to their new life in the community, agencies reported that 71% of the people moved with little or no adjustment challenges and 29% required moderate or significant help in adjusting to their new settings. Participating agencies further reported that most people adjusted in 1-3 months and all but 3 had adjusted within 12 months of the move.

Of particular importance it was found that most people were receiving the medical/professional resources their planning listed as required and often these resources exceeded the recommendations or needs. However there were still some gaps for some people.

Participating agencies indicated that the majority of people are involved and participating in their communities although some with limitations. Agencies feel that 60% of the people have good to excellent day programs although 11% are poor or need improvement. The staff of the agencies reported that most of the people were in good to excellent environments but 14% are in environments that are only adequate.

An interesting component of the research compared how families view quality of life issues compared to how agencies view the same issues. Slightly more agencies than families (91% to 87%) view the quality of life of people as good to excellent on the scale provided.

## **FOCUS AND INTERVIEW GROUP STUDY**

The Focus and Interview Group Study involved 40 people including families, planners, facility staff, community staff and behavioural consultants.

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Some of the comments made through this particular study included:

- A general satisfaction with the community placements with the exception of those placed in long term care facilities. (Only 1% of the residents were placed in long term care facilities.)
- Some concern was expressed about losing the medical resources of the institution but others talked about the quality of community medical resources.
- Former facility residents were described as being happy in their new homes.
- Family contact and involvement increased.
- There were reports of decreased use or elimination of restraints along with a reduction in physical and medication interventions.
- There were more opportunities for people to exercise individual choice.
- People demonstrated skills that were not anticipated and people are doing things that no one imagined they could do.
- There were improvements noted in the physical and mental health of former residents now that they were living in the community.
- People who lived in the institution were more resilient than people gave them credit for and now that they are in the community they have adapted beautifully.
- There was a considerable reduction in challenging behaviours once people had more options, exercised more choice, experienced improved communication, had their preferences respected, etc.
- Good planning for the transition is critical.

## CONCLUSION

Overall, this summary of the Report of the Facilities Initiatives Study presents a positive picture of the Ontario closure experience, however the authors of this article would like to add the following observations.

- It should be noted that while the majority of families and agencies were more than satisfied with the process, some people had concerns. The results also indicated that some placements and supports were not rated as even satisfactory. Hopefully those concerns will be addressed at different levels.
- An important observation the researchers noted was that: “Less than positive outcomes were not related to the functioning abilities of the individuals but to the **transitional process** that was followed and the **philosophy and approach of the receiving agency.**”
- During the presentation in Halifax the researchers noted some of the families involved in a class action lawsuit to stop the closures were among those satisfied once their relatives moved to the community.
- The researchers also commented that some families visited their relative living in the community less often than when he or she lived in the institution as they felt they were safer in the community and there was not the same need to visit.

We look forward to learning more about the results of the Intensive Case Study and the Quasi Longitudinal Study, where more voices of the people who moved will be heard.

Other jurisdictions in the country that still hang on to an institutional model that keeps people with intellectual disabilities congregated and isolated from their families and their communities can and should learn from this study. While overwhelmingly positive outcomes were achieved, there are lessons to be learned from Ontario's experience and improvements that can be made when other jurisdictions proceed with their own institutional closures. With appropriate transition planning and adequate and individualized supports provided, positive outcomes are indeed achievable for everyone.



## PROVINCIAL / TERRITORIAL UPDATES

### ONTARIO

In 2009 Ontario celebrated the closing of our last three government institutions for people who have an intellectual disability. It was a long struggle, lasting well over thirty years and numerous governments (representing all three political parties) since government first announced a commitment to end institutional life.

At Community Living Ontario's annual meeting in June of 2009 Gordon Ferguson proposed a resolution to create a Watchdog Function within the Association to make sure that institutions never again became a reality in Ontario. The resolution received unanimous approval. Gordon had a personal interest in the issue, himself being a survivor of institutionalization for several years of his life. He and his wife Donna live in their own home in Brockville in eastern Ontario and are true believers in a good life in the community for everyone.

This year Community Living Ontario strengthened the Watchdog Resolution by turning it into a Policy Statement that commits the Association at all levels to identify **"any proposed or existing programs or services...that because of size or other factors are institutional in nature"** and that once identified an investigation will be conducted and steps will be taken to **"stop or promote the redesign of the program or service in ways consistent with the Values and Goals"** of the Association.

This is a challenging task taken on by Community Living Ontario in order to promote the right of all people to have a good life in community.

### NOVA SCOTIA

In August of 2011 a roundtable of community and government people was tasked by the Minister of Community Services to develop a framework around community living to be presented to the Nova Scotia Cabinet.

Roundtable meetings were cancelled; the group was then disbanded, only to be reinstated a few months later. Then we were advised that a redesign of the Continuing Care / Services for Persons with Disabilities (CC/SPD) was to take place.

It was, however, seven months later before our next meeting took place (July 5th 2012). To say that we were disappointed would be an understatement. At this meeting, instead of engaging in conversation or seeking our input, government representatives presented us with the four key principles that they had already decided would guide the CC/SPD redesign.



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- Adopt a person-focused approach;
  - Expand and enhance home/ community based services;
  - Increase integration/ coordination;
  - Implement cost-effective initiatives

The department has no staff dedicated anymore to this redesign...but they plan to have a discussion paper finished by August, consult with stakeholders by the end of September and have recommendations to Cabinet by November 2012.

NSACL's response has been quick to express our disappointment and outrage at the delayed consultation process for the "CC/SPD" redesign and the lack of response from the government for community dialogue and discussion.

We have written government to have input into the discussion paper so that it truly reflects the wisdom and experience of those living with intellectual disabilities in Nova Scotia.

NSACL believes a model of long term community supports should be representative of known Best Practices and reflect the following Principles:

- Commitment to a comprehensive time-lined plan to ensure that institutional models of residential supports are no longer an option for Nova Scotians with intellectual disabilities—and that all supports essential for full inclusion are secured and readily accessible in their home communities
- Commitment to zero expansion of "bricks & mortar" (including renovations of existing institutions) with "due regard" to employment, health and safety issues
- Flexible, negotiable and individualized supports (as opposed to fixed models or continuum of services)
- Community based choices that are socially inclusive and person-centred
- Leadership through a quasi public entity, with leaders steeped in values of social inclusion and who recognize and understand the unique support needs of individuals with an intellectual disability
- Value-based training for staff
- Sustainability for future initiatives such as the development of community-based options in local communities — creating new jobs and supporting the neighbourhood economy

We have urged the government to incorporate these principles in the Discussion Paper to be released at the end of August. As equal partners, we are ready for a meaningful dialogue as we move forward with increased innovation, consultation, options and choices, action; and a new hope for the future.

In the meantime a second floor is being built on a renovated institution in the province. Given this, one questions whether the Department of Community Services' (DCS) commitment to community-based Services for Persons with Disabilities is slipping away? Government documents indicate our concerns may be justified. In figures recently released (Volume 3 of the Public Accounts for 2011-2012) payments were listed by DCS to various institutions. When compared to payments from 2009-2010, spending on what appears to be institutional care grew much faster than spending on the Services for Persons with Disabilities program as a whole. **Institutional spending increased twice as much (12.8% vs 6.4%) as spending on other SPD programs.**

**Our work continues...**

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## ALBERTA

Over the last forty years, Alberta has substantially reduced its institutionalized population from thousands to a few hundred while today providing supports that enable more than 15,000 children and adults with intellectual disabilities to grow up at home and live in the community. Alberta has some of the most progressive policies in Canada which enable children and adults with intellectual disabilities to receive supports designed around their unique needs. The supports enable children to remain in their family home, attend school and participate in community activities the same as their peers. Adults with intellectual disabilities are also able to receive supports that enable them to live in their own home, attend university or college, obtain employment or engage in other meaningful activities.



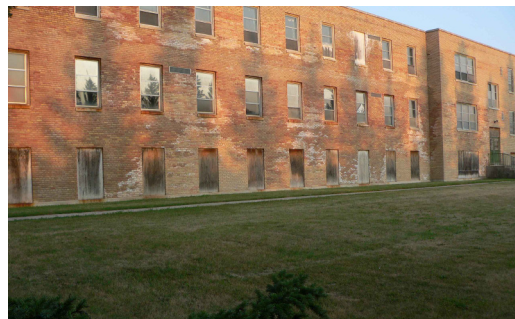
The transition from institutional care to supporting people to live in the community has not been without its problems. Alberta still has community programs that continue to segregate and de-value people. At times the province has implemented programs for the sake of efficiency and cost containment that by their very nature make it impossible for people to be seen as equal members of our society. The challenge we face is not only to see every individual remaining in an institution return to community but also to transform many community services so they truly support individuals to be equal contributing members of our society while capitalizing on communities' capacities to include individuals.

There is growing discontent and recognition across the province that government needs to act with integrity and provide the supports every institutionalized individual requires to live in the community. Supports need to be designed around individual needs and funding by government should enable people to live in their own homes and not be congregated in facility based programs such as institutions or group homes.

The Government of Alberta has recently moved the Persons with Developmental Disabilities Program Branch from the Department of Seniors and Community Supports to the Department of Human Services. The Honourable Frank Oberle has been appointed Associate Minister and has been given responsibility for the Persons with Developmental Disabilities Program. In her announcement of the appointment of the Associate Minister, Premier Redford stated, "Albertans have given this government a mandate for change. They expect us to deliver on a bold agenda". It is hoped that this bold agenda includes the return of the remaining few hundred individuals with intellectual disabilities currently institutionalized to community, the then closure of these empty facilities and the development of a strategy to transform our current community supports system. The challenge before us is not to replicate the past but to transform our services and communities to enable people with disabilities to live meaningful lives as part of the fabric of our society.

## MANITOBA

As news bulletins of institutions closing in other jurisdictions come in on a regular basis, it is disheartening that the Manitoba government remains steadfast in their opinion that institutional living remains a necessary option for some people. In Manitoba, there are over 5,000 people who live beside other members of the community, who participate fully in all activities in a meaningful way. Their presence contributes to the community's health on many levels. They are





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exercising their right to live in the community as guaranteed by the UN Convention on the Rights of People with Disabilities, but approximately 250 people living at Manitoba Developmental Centre are waiting for their turn.

The good news is sixteen people will be leaving MDC to take their rightful place in the City of Portage La Prairie. New Directions Inc. has been working with the transition team since the Spring to support people to move into their new homes. To date, eight people have moved back to community, with an additional eight more people expected to move before the end of the year.

With all lifestyle changes people need a period of adjustment. We know the stories of their transition are unfolding and we will be able to share their news and celebrate their return to their community very soon. We hope to share some of these stories in the next edition of *Institution Watch*.

Manitoba is fortunate to have many agencies that are ready to welcome people and who have committed staff members who are willing to go the distance to ensure that people are respected, treated well and have their dreams come true.

The number of people who continue to live in institutions in Manitoba is approximately 450 not counting people who are inappropriately placed in Personal Care Homes.

## SASKATCHEWAN



On February 24, 2012, the Minister of Social Services, Honourable June Draude stated, “The Province of Saskatchewan will begin planning and consultations with residents of Valley View Centre, their families and key stakeholders for new services to replace the current Valley View Program.” Following this announcement a Valley View Centre Transition Steering Committee was formed. The membership of this committee includes the Saskatchewan Association for Community Living (SACL), Valley View Centre Family Group (VVCFG) and the Ministry of Social Services (MSS), with Doug Conn, VVCFG co-chair as the chairperson of the Transition Steering Committee.

The government has chosen to consult with community organizations and stakeholders throughout the planning process. The SACL is not only involved at the steering committee level, but also at the transition planning team level. Nicholas Fraser, SACL’s Housing Initiatives and Research Coordinator has been engaged with the transition planning team since its formation, and will be SACL’s project lead on site for the Valley View Centre Transition Planning.

The Ministry of Social Services has further supported SACL to hire two Transition Plan Advocates, Wanda Jonas and Roberta Ross. Wanda and Roberta will provide support and act as a resource to individuals with intellectual disabilities and their families during the planned transition from the Valley View Centre in Moose Jaw to their new homes.

The Transition Plan Advocates will continually be engaged with the residents and staff at Valley View Centre. Their office is located at Valley View Centre; allowing them to be easily accessible and available to residents,



and greater opportunity to foster relationships with residents, family and staff. The Transition Plan Advocates will also be a part of all transition planning and team meetings for individuals who do not have family members to support them through the process, and where the family or the individual has requested SACL to be present.

The Valley View Centre Transition Steering Committee and Planning Team has also been actively exploring residential options to better enable success and provide more choice for the residents of Valley View Centre. Recently, members of the transition planning team toured Manitoba; consulting and gathering information from a number of organizations and individuals.

The Saskatchewan Government has chosen to partner with SACL and VVCFG. Through this partnership we are able to hold each other accountable; ensuring each resident has an individual plan that will maintain his or her quality of life, and minimize any potential negative impacts the transition may have on the individual.

The SACL thanks the Government of Saskatchewan for including us in the transition process in a very thoughtful and authentic way. This process and transition is unique to Saskatchewan and will work to deliver the government's vision and goal to make Saskatchewan the very best place in Canada to live for those with disabilities.

## BUSTING OUT

(a poem by Daniel Beimers)

*Walls slowly growing closer,  
the room growing smaller,  
restraining, isolating, its cold,  
its impersonal, forced medication,  
restrictions, a group mentality.*

*But that's the old way,  
inclusion, freedom, living level headed,  
having friends,  
being an individual,  
a say in what we do and when to do it  
(within reason).*

Daniel composed this poem during the conference of People First of Ontario in October of 2011 after a session that explored how people need the opportunity to heal after their experiences of living in institutions. Daniel lives in western Ontario and is a member of People First of Middlesex.

## NEWFOUNDLAND AND LABRADOR

### Do we remember our history?

After a struggle of more than 50 years to support people with intellectual disabilities to secure their rightful place in community and to live meaningful lives in community, are we at risk of going backwards? Are the gains made, and the advances in our understanding of the needs of people with intellectual disabilities now at risk?

As a country we have come far in our efforts to support people to live in community. No longer is institutionalization seen as a natural response to disability. Newfoundland and Labrador can be rightly proud of its contributions to the closure of institutions and to advancing independent/supportive community living.



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In reference to people living in their own homes, Premier Dunderdale said during our recent provincial election, 'better for you, better for us'. Indeed, similar comments were made by the Premier of Ontario. The policy, the philosophy and the values associated with community living seem to be intact. What is not in evidence, however, are the financial and planning commitments, at both a provincial/territorial and federal level, that balance the need of the long term care sector and that of supportive community living.

Most individuals and their families are deeply concerned for what they see happening and what they fear will happen in the future. Quietly, young people are finding their way into personal care homes, senior's long-term facilities and even hospitals. People with intellectual disabilities and their families have fought long and hard, here in this province and throughout the country, to reject the use of institutions. It was a victory we thought we had achieved. Yet today's reality indicates that we yet once again may have to battle against the institutionalization of our sons and daughters.

Hundreds of millions of dollars, newly budgeted dollars, are being invested in long term health care and very little into supporting people to live in their own homes in the community.

While the pressures are clearly in place to meet the needs of the population of those needing long term care, many feel we are losing the lesson of history. Many are questioning the increased role being given to buildings and institutions rather than to investment in and strengthening of community supports.

The necessary investments and dialogue leading to strategies to preserve people's abilities to live in their home, with supports if required, are not yet evident. If this continues the Premier's statement of belief will not continue to be the reality for many people.

Newfoundland and Labrador built a comprehensive community based Health Care System. It was a system that, for a while, was responsive to the needs of people with intellectual disabilities and their families. There are increasingly high numbers of individuals and families wondering if that history is well remembered and valued. The danger is we will starve the current system so badly that it collapses. Then once we have people back in expensive non-productive institutional settings, it will occur to us that what is needed is a community based health care system.

There are many within the system who say that community supportive services have the highest priority. Sad to say, however, it is not a shared view. Everyone knows the pressures on health care budgets and the competing priorities. It is about choices based on sound thinking, fairness and values.

The lost history may have us going down a very expensive road, with dire consequences for individuals, unless we can re-visit our commitments and our priorities.

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## UNITED NATIONS 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:

- 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.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into force in 2006, and since that time has been ratified by 119 countries. Canada signed the CRPD in 2007, and ratified the convention in 2010.

Within the Canadian context, the CRPD does not establish new rights. These same rights are also provided for in our Canadian Charter of Rights and Freedoms and the Canadian Human Rights Act. The Convention does however articulate what existing human rights mean within a disability context. The purpose of the CRPD 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’.

Article 19 of the Convention is very clear in its message. In order to live and be included in community people need to have choice in where they live and with whom. The Convention recognizes that to live meaningful lives in community people may require various types of supports and services, and describes the need for inclusion in community.

Canada has signed and ratified the Convention and thus has committed to compliance with the Convention. Such compliance applies also to provinces and territories within this country. Yet daily we hear of people with intellectual disabilities being placed in long term care facilities, nursing homes, etc. without choice or options; individuals and families who are told that needed supports are not available, that they are not eligible or that they will be placed on a waiting list; daily we hear of people with intellectual disabilities living in poverty and isolation. Why is that? Where is the choice, support and inclusive lives promised by the Convention, and through its ratification, also promised by Canada?

## CALL FOR CONTRIBUTIONS

We encourage you to submit stories, Provincial/Territorial updates, pictures and /or personal perspectives on this issue. Please send all contributions directly to Don Gallant at [dgallant@nl.rogers.com](mailto:dgallant@nl.rogers.com) for publication in our next edition (due out in Winter 2012).

### ***Have you signed the Declaration of Support for Community Living?***

This Declaration of Support for Community Living can be accessed at

<http://www.institutionwatch.ca/>

Please visit this site and sign our declaration, and the Task Force would ask that you share this site among your various organizations and networks.

WE, INDIVIDUALLY AND COLLECTIVELY, commit to working together to assist persons to return to their communities and call on all levels of government in this country to:

- Acknowledge that institutions for persons with intellectual disabilities have no place in today's society;
- Stop financing or otherwise supporting the establishment of new institutions for persons with intellectual disabilities;
- Stop all new admissions to existing institutions;
- Support the right of all people with disabilities to live in the community as equal citizens;
- Commit the necessary resources to support the development of quality, comprehensive community-based alternatives to institutional care;
- Acknowledge the wrongs that have been committed against those individuals who have been held for far too long in institutions across this country.

## ACKNOWLEDGEMENTS

CACL and People First of Canada gratefully acknowledge the Government of Canada (Social Development Partnerships Program – Disability Component) for supporting our national Community Inclusion Initiative.

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