

inclusion of Canadians with intellectual disabilities

a national report card

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Diversity includes.

message from the Canadian Association for Community Living

In the last 50 years we have seen the rights of persons with intellectual disabilities recognized – in the Charter of Rights and Freedoms, Human Rights Codes, legislation, public policy and most recently, in the United Nations Convention on the Rights of Persons with Disabilities. These advancements tell a story of the Canadian values of inclusion, respect, and diversity. However, the situation of people with intellectual disabilities also tells us that there is a gap between our values and practice. This National Report Card makes it clear. The attainment of full inclusion for Canadians with intellectual disabilities is far from complete. We invite and challenge each of us, as Canadians, to hold our communities, our governments and ourselves accountable for taking action to close this gap.

why a report card?

In 2005, the Canadian Association for Community Living (CACL) adopted a bold ten-year, ten-objective agenda to guide Canadians and our governments in building a more inclusive Canada. Those objectives are:

1. **Achieve Equality Rights and Recognition**
2. **Close Institutions and Assure a Home in the Community**
3. **Secure Child Rights and Needed Supports**
4. **Ensure Families have Needed Supports**
5. **Achieve Inclusive Education**
6. **Secure the Right and Access to Disability Supports**
7. **Establish Safe and Inclusive Communities**
8. **Eradicate Poverty for people with intellectual disabilities and their families**
9. **Achieve Employment Equality**
10. **Make a Global Impact on Inclusion**

While these goals cannot be fully realized within 10 years, a decade of commitment and change could make a significant difference. But first, Canadians must know where we are today and where we are going. The National Report Card on Inclusion will annually track and evaluate progress towards the attainment of these objectives.

This 2007 Report Card examines how we, as a country, measure up on four of these 10 objectives: Close Institutions, Secure the Right and Access to Disability Supports, Ensure Families have Needed Supports, and, Achieve Inclusive Education.

A full report on all 10 objectives, coinciding with CACL's 50th anniversary, will be issued in November 2008.

status of Canadians with intellectual disabilities

There are almost 1,000,000 Canadians living with an intellectual disability, of every age, in every community in this country. Together with their families, they comprise a sizable portion of our Canadian public.

In many communities, we see people with intellectual disabilities:

- Growing up, belonging and valued, within their families and communities;
- Experiencing inclusive lifelong learning;
- Actively involved in the labour force and earning a decent wage;
- Contributing in meaningful ways to their communities and country.

However, this experience remains limited. All across Canada, many continue to be excluded and marginalized. Despite the positive lived experience of many Canadians with intellectual disabilities and their families, despite numerous success stories, despite our vast knowledge and understanding of best practices and what makes inclusion work, despite progress made in the past 50 years, for far too

many Canadians the experience of disability remains one of exclusion, isolation and poverty.

We know that here in Canada:

- Thousands continue to reside in inappropriate institutional environments.
- Only 33% of Canadians support inclusive education for students with intellectual disabilities.
- Almost 30% of children and youth are segregated in special classes or schools.
- Over 75% of adults with intellectual disabilities live in poverty.
- Over 60% of adults with intellectual disabilities are unemployed or out of the labour force.

In Canada we pride ourselves on having diverse, inclusive societies. Diversity and inclusion are foundational principles that we celebrate and strive to achieve. Across the country, on a daily basis, people with intellectual disabilities and their families demonstrate to Canada that “inclusion” is possible. That it is nothing special. It is simply people living, and being allowed to live, their everyday lives as valued members of their community.

CACL believes in this vision of diverse and inclusive communities. The real strength of our families and communities comes from our diverse array of interests, skills and abilities. Truly diverse communities are the ones where all people are included and valued in their daily lives.

As a country, we are leaving Canadians with intellectual disabilities and their families out. This lessens their lives, it lessens all our lives.



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closing institutions

Our Vision:

Close Institutions – Assure a Home in the Community

People with intellectual disabilities are free from confinement. All institutions for people with intellectual disabilities are closed. People live in homes of their choice, with appropriate supports.

Why this Vision

Institutions deny people basic rights of citizenship, personal control, decision-making, and independence. People who have lived in these facilities tell of the abuse, isolation and suffering that occurs. An institution represents an approach that denies choice, denies opportunity; congregates, segregates and isolates people. An institution can never be a “home”. A home is a place where we like to be, somewhere we feel comfortable, safe and in control; a place that provides personal space, and where we can enjoy family and friends. Our homes root us in community and add to our identity.

Benchmarks to measure progress

To ensure this vision is achieved, the following benchmarks must be met:

- Halt further admissions to large institutions.
- Close all large institutions for people with intellectual disabilities.

“It was never explained to us, they just said we were going on a trip and instead we were sterilized.”

— Former Resident, Michener Centre

“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 in I'd be in for life. There are a lot of people who are in there for life. I'm better out”.

— Former Resident, PEI Institution

- Ensure people with intellectual disabilities are not inappropriately living in other institutional settings like nursing homes etc.
- Ensure that all supported living options are based on choice, self-determination, and individualized funding.

How Canada is measuring up *Making the Grade...*

- Substantial progress in downsizing and closing institutional facilities over the last 20 years has significantly reduced the number of people living in large institutions.
- Newfoundland and Labrador, New Brunswick and British Columbia have successfully closed all large facilities designed for people with intellectual disabilities.
- Ontario, Canada's largest province, will close its remaining three large institutions by March 2009.
- Yukon, Northwest Territories and Nunavut do not have any large facilities.

*Nobody who lived there and got out has ever said,
'Boy, I'd really like to go back and live there again.'
Nobody. Not one. That tells you something.*

— Former Resident, Valley View.

Improvements still needed...

- Institutions designed specifically for people with intellectual disabilities and housing more than nine persons still exist in eight provinces – Nova Scotia, Prince Edward Island, Quebec, Ontario, Saskatchewan, Manitoba, Alberta and British Columbia.
- More than 2,600 persons with intellectual disabilities still reside in facilities designed to house nine or more individuals.
- Nearly 2,000 people still live in facilities designed to hold more than 100 people.
- In comparison to activity in the 1990s, efforts during the past decade to close remaining institutions have slowed and/or ceased.
- Manitoba and Nova Scotia have announced new investments in institutions.
- Saskatchewan and Alberta have indicated continuing support for an institutional component as part of its service delivery system.

Our Assessment

While there has been some progress in closing institutions in this country, too many people with intellectual disabilities remain in institutional environments and there is still no consistent approach or understanding of how to assist people to move from institutions to communities. The unfortunate reality is that in recent years, the death rate in some institutions exceeds the number of community discharges.



- The majority of provinces and territories were unable to provide accurate information in relation to admissions or discharges.
- Accurate statistics are not available on the numbers of persons with intellectual disabilities known to be living in other institutional environments such as Nursing Homes, Acute Care Hospitals, Personal Care Homes / Special Care Homes, Senior's residences, Rehabilitative Centres or other long term care facilities in all provinces and territories. Conservative estimates indicate this number to be in the thousands.

The numbers presented, while alarming, do not reflect the true extent of the institutionalization of persons with intellectual disabilities in this country.

Overall, the data indicate that our governments and communities are not meeting the necessary conditions to ensure that people with intellectual disabilities are able to realize their right to live in the community.



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achieving inclusive education

Our Vision:

Achieve Inclusive Education

All people with intellectual disabilities are fully included with their peers in regular education, with appropriate supports from early childhood through to post secondary and adult life-long learning.



Why this vision

Lifelong patterns of inclusion are established in early childhood education programs, pre-schools, in the classrooms and on the playgrounds of neighbourhood schools. Research reveals that children who are included in their early years have better outcomes for inclusion as adults. When children and youth with disabilities grow and learn alongside their peers, they are more likely to: continue in education, get a job, and be included and valued in their communities. They also have expectations that they are going to belong. Research has shown that inclusive education is better for all children. Children learn what they experience; inclusive education settings enable children without disabilities to learn about diversity and respecting and valuing all people.

Benchmarks to measure progress

To ensure this vision is achieved, the following benchmarks must be met:

- Effective inclusive practice is the norm in classrooms, schools and post secondary educational systems across the country.
- Educational policy and programming promotes and supports inclusive education.
- Broad public support exists for inclusive education as an essential aspect of a quality education for all children.

“It seemed that once an educational assistant (EA) was trained, understood [my son’s] efforts to communicate, and was fully ready to provide quality support, she was bumped or moved voluntarily somewhere else. Over the period of a few years, [my son] had six different education assistants.”

— Family member, British Columbia

“... A process has begun that will see the development of a shared philosophy of inclusive educational practices within the context of safe and caring schools...”

— Provincial Department of Education, Newfoundland and Labrador



How Canada is measuring up

Making the Grade...

- Over 70% of parents whose children with intellectual disabilities are in regular classrooms report that their children are doing average or better.
- Students with intellectual disabilities in regular classes are more likely than their counterparts in other educational arrangements to be:
 - Socializing with other children and youth at school during recess or lunch hour;
 - Interacting with school friends at home and elsewhere after school;
 - Taking part in school activities and outings beyond the classroom, and extra curricular activities at recess, lunch and after school.

Improvements still needed...

- Almost 30% of students with intellectual disabilities are segregated in special classes or schools.

Our Assessment

Despite generally progressive and positive views about inclusion in communities, Canadians continue to express limited support for the full inclusion of children and youth with intellectual disabilities in schools. Given this, it is not surprising that families and students strongly indicate that access to inclusive education remains a daily challenge. Further,

- Students with intellectual disabilities are half as likely as students with other disabilities to be only in regular classes and four times more likely to be only in special education.
- Parents report that regardless of placement, the overall level of interaction with other children is less than satisfactory.
- Only 33% of the Canadian public is fully supportive of inclusive education of children with intellectual disabilities.
- Altogether absent or inconsistent provincial and territorial collection and reporting of administrative data on numbers of children by type of disability and type of educational arrangement.

research indicates that despite educational policy to support inclusion, approaches to implementation are inconsistent and vary considerably from region to region and school to school. A shift in program and practice is needed to realize inclusive education. General awareness raising about the successes of properly implemented inclusive education is also needed to increase public support.



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supporting families

Our Vision: Ensure families have needed supports

Families access the supports and opportunities they need to assure inclusion for family members with intellectual disabilities through their lifetimes, and to secure family, social and economic well-being.

Why this Vision

Families provide the bedrock of caring relationships, mutuality and reciprocity for each family member over their lifespan. They provide a foundation of support that advances the self-determination and unique life path of each family member. It has been estimated that the economic value of the contributions of families and friends would total more than \$5 billion annually if delivered by a paid workforce. Families value their support role but cannot, realistically, be expected to provide this support on their own. Families need supports that supplement not replace the support provided to their family member with a disability. They require community supports and systems — childcare, health and social services, physical and social infrastructure in the cities and communities in which they live, access to transportation and a wider network of social relationships and social capital they can draw upon for support.



Benchmarks to measure progress

To ensure this vision is achieved, the following benchmarks must be met:

- Families have access to needed supports and services to meet the needs of their family (i.e. respite, in-home support, and home modifications).
- Policies are established, and implemented, that ensure families can play their caregiving role and at the same time participate in the paid labour market, advance in their careers, and have the option to withdraw from their primary caregiving role as their family member enters adulthood.
- Strong incentives are in place for families to: plan for and invest in the future financial security of family members with disabilities; and to ensure that any financial benefits that result do not negatively impact on their family member's access to government-funded income support programs.

"...[Our son's nanny's] devoted presence has also allowed me "to have a life" and allowed me to continue to work and earn an income."

— Family Member, British Columbia

- Governments and communities are investing in a sustainable local-to-national capacity for family leadership, empowerment and networking that advances the citizenship and inclusion of Canadians with disabilities.

“I bring my son everywhere, I never was ashamed of him I never will be and he is very well known and liked in the community.”

— Family Member

How Canada is measuring up

Making the Grade...

- Families receive some financial support through the tax system, for example the Disability Tax Credit, the Medical Expense Tax Credit, and the Caregivers Tax Credit.
- The Government of Canada has announced a Registered Disability Savings Plan to assist in securing the long-term economic security of people with severe disabilities.
- The Government of Canada’s Compassionate Care leave benefit offers support and employment security to families supporting a family member who is gravely ill or dying.
- While not uniform across the country, all provinces and territories do make available to families a variety of supports and services such as respite, home supports, etc.

Improvements still needed...

- Children with disabilities are disproportionately over-represented in

provincial/territorial child welfare systems — demonstrating the impact of inadequately supporting families.

- Nearly half of parents who have a child with an intellectual disability have either refused a job, have changed their hours of work or have worked fewer hours so they can care for their children.
- A quarter or more parents of children with intellectual disabilities quit working, refused a promotion or had money problems due to their child’s disabilities.
- Parents of children with intellectual disabilities are more than twice as likely as parents of children with other disabilities to indicate the need for more help with housework, or supports so they can have time for other family responsibilities and for personal activities.
- Adults with intellectual disabilities are over twice as likely as others to still be living at home with one or more parents.
- Adults with intellectual disabilities are 2.6 times more likely than non-disabled adults to live in low-income families.

Our Assessment

Despite modest investments in families via the tax system, the picture of supports for families remains disturbing. The data show the major role family members play in providing practical support to family members with intellectual disabilities — much of it informal, unassisted and uncompensated. Without adequate support, families supporting a family member with a disability have a greater likelihood of living in poverty; face exclusion from the labour market;

have a more difficult time keeping their jobs; experience increased out-of-pocket expenses for their family members; face exclusions from benefits and employer-based insurance as well as a loss of pension benefits for those who stay out of the labour market. We know that families supporting a family member with a disability need better, more flexible supports to respond to their family member’s disability-related needs.



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accessing disability supports

Our Vision:

Secure the Right and Access to Disability Supports

All people with intellectual disabilities have access to, and acknowledgement of, the disability-related supports they need to live meaningful lives and contribute as full citizens.

Why this Vision

Access to disability-related supports is a foundation to realizing the full inclusion of people with intellectual disabilities. Access to disability-related supports enables people with intellectual disabilities to go to school, gain and maintain employment, and live and participate in the community as valued, equal citizens.

Despite the fact that disability supports is predominantly in Provincial/territorial jurisdiction, we believe that disability is best understood as a citizenship issue and that there is shared FPT responsibility in ensuring that Canadians with disabilities and their families have access to the disability supports they require to be full and active citizens.

Further, the federal government has been a partner in developing the existing systems of support and services through cost-sharing

Disability supports are defined as: any good, service or environmental adaptation that assists people with disabilities to overcome limitations in carrying out activities of daily living and in participating in the social, economic, political and cultural life of the community.

programs and block transfer funding mechanisms. Accordingly, the federal government has a responsibility to assist provinces to transition from outdated, institutional systems of support to a system that is innovative, flexible and responsive to the individual needs of persons with disabilities.

Given the transformational role access to adequate and appropriate supports can have on the lives of people with disabilities, the disability community has made disability supports their number one priority.

Benchmarks to measure progress

To ensure this vision is achieved, the following benchmarks must be met:

- Canadians with intellectual disabilities have access to needed disability-related supports.
- Disability-related supports are portable, flexible, and individualized.
- Entitlement and access to disability-related supports is not means-tested.
- Increased investment by governments in disability supports and capacity of communities.

“I receive supports from staff when I need them. I am able to do things independently when I’m given the opportunity. People with disabilities can do almost anything if given the chance and the supports they need.”

— Person with an Intellectual Disability



How Canada is measuring up

Making the Grade...

- “Disability Supports” are one of three building blocks identified in *In Unison*, the Accord of federal/provincial/territorial governments on disability.
- While not uniform across the country, all provinces and territories do make available to individuals a variety of disability-related supports and services.
- Progress has been made in many provinces and territories to reform supports and services to be based on principles of flexibility, self-determination and individualization.
- Some provinces have separated access to disability supports from the income support system.
- In recent years, the FPT Working Group on Benefits and Social Services and the First Ministers of Social Services committed to making disability a priority and to exploring a number of options to address disability and income supports.

Improvements still needed...

- More than 30% of people with intellectual disabilities report unmet need for help.
- Costs of disability related support and lack of insurance coverage are reported as the main reasons why people with disabilities lack the help they need.
- The extent and type of available disability related support varies from province to province.
- People with intellectual disabilities report that current systems of support are too often rigid and unresponsive to their individual needs.
- In most provinces and territories, eligibility for disability supports is linked to income levels of the individual with a disability or their family.
- Despite prior commitments, no substantive action has been forthcoming from the FPT deliberations.

Our Assessment

While we know that access to needed and appropriate disability supports can be transformational in the lives of people with intellectual disabilities, too few people are able to access all the supports they need in ways that best suit their needs. In many ways access to

disability supports will determine the life opportunities and outcomes for people with disabilities. The denial of disability supports is fundamentally a denial of opportunity to be a contributing Canadian citizen. For too many, the result is poverty, exclusion and isolation.



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conclusion

The analysis of these four priority areas leads to one conclusion: the inclusion of people with intellectual disabilities is both possible and achievable, yet still not a reality for most people. The many meaningful examples of people with intellectual disabilities living valued lives as contributing members of their communities serve as a reminder of what is possible. This is the vision of inclusion we strive for — the vision that can be a reality for all.

The data show that this vision is not a reality for a majority of people with intellectual disabilities. It is clear that Canada is failing to create an inclusive and accessible society where people with intellectual disabilities and their families are adequately supported and enjoy full citizenship.

There are many opportunities available to all levels of governments and communities to take the necessary steps to address this situation. The personal, social and economic costs of exclusion are simply too high to be ignored. Further, it is morally unjustifiable in a prosperous country such as Canada that people with intellectual disabilities continue to face staggering rates of poverty, isolation and exclusion.

Immediate action is needed to ensure that people with intellectual disabilities and their families are no longer invisible and marginalized. Collective will is needed to take the next major steps in the journey of inclusion. People with intellectual disabilities should not have to wait any longer to realize their rights as citizens of this country.

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