

inclusion of Canadians with intellectual disabilities



Message from the Canadian Association for Community Living

The Canadian Association for Community Living (CACL) has a vision for Canada in 2020. A vision based on principles of inclusion, dignity and respect; a vision that celebrates diversity and views disability as part of our rich heritage and promising future as a country; a vision of a fully inclusive and accessible Canada.

Canada's ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) represents a new era for disability rights in Canada and internationally. The CRPD provides individuals, communities and all levels of government an opportunity to write a new history, and future, of disability. To turn a corner on the staggering rates of poverty people with disabilities and their families face; to right the wrongs of our institutional history; and to correct the course of our outdated custodial approach to supporting people with disabilities.

It is time for a new story of disability in this country. The story that poverty, isolation and marginalization are the likely outcomes of life with a disability should have no place by 2020.

The 2010 National Report Card confirms that there is much work to be done to achieve that vision. It also highlights that inclusive education and access to

disability supports – for individuals and families – are critical in writing a new future for Canadians with disabilities.

Preparing that future starts now and all Canadians have a responsibility to help shape it. Persons with intellectual disabilities and their families cannot do this alone. CACL challenges and invites all Canadians to join us in building a truly inclusive and accessible Canada.

To guide us toward this future, CACL has adopted the following ten point agenda to guide Canadians and our governments in building a more inclusive Canada. These 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*

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 for all children are established in the early years – family life, early childhood education programs, pre-schools, in the classroom and on the playgrounds of neighbourhood schools. Research reveals that children with intellectual disabilities who experience early years inclusion have inclusive outcomes 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 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:

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

What is inclusive education?

CACL understands inclusive education to mean that all students attend and are welcomed by

their neighbourhood schools in age-appropriate, regular classes and are supported to learn, contribute and participate in all aspects of the life of the school. Inclusive education is about how we develop and design our schools, classrooms, programs and activities so that all students learn and participate together.

How Canada is measuring up

Making the Grade...

- Article 24 of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires Canada to establish an inclusive education system at all levels.
- 38% of children with intellectual disabilities receive early learning and child care services.
- Children with intellectual disabilities are generally enrolled in the public school system (95% of children aged 5 to 14 years are attending school or kindergarten).
- The vast majority of parents (94%) feel that they are made to feel welcome in their child's school.
- Children with intellectual disabilities in high inclusion school settings report excellent or very good health (78% as compared to 49% in low inclusion school settings).
- When participating in high inclusion school settings children with intellectual disabilities report doing 'very well' or 'well' at interacting with their peers (56% as compared to 38% of those in low inclusion school settings).
- 74% of children with intellectual disabilities in high inclusion settings look forward to going to school (compared to 63% of those in low inclusion school settings).
- Typically more than 70% of students with intellectual disabilities who complete post-secondary education go on to secure immediate employment.
- Some jurisdictions have post-secondary institutions offering fully inclusive post-secondary educational studies (e.g. in Alberta there are 17 such facilities).

Improvement still needed...

- Among children with intellectual disabilities receiving early learning and child care services, 32% have been denied this service at some point in the past.
- 30% of children with an intellectual disability had to leave their community in the past twelve months in order to attend school.
- Only 33% of children with intellectual disabilities are in high inclusion school settings.
- Children with an intellectual disability are four times more likely than other children with disabilities to be attending special education schools (16% vs. 4%).
- 41% felt threatened at school or on the school bus within the past year and more than a third



(36%) were assaulted at school or on the school bus.

- 52% of young adults with an intellectual disability (aged 20 – 29 years) are neither working nor attending school, compared with 12% of those without a disability.
- Young adults with intellectual disabilities are five times more likely than those without disabilities to have no formal education certificate.

Our Assessment

Despite continued research and practice that demonstrates inclusive education is better for everyone, students with intellectual disabilities are still not fully included in schools. Inadequately supported school and classroom efforts for inclusive education has damaged public perceptions about what inclusive education looks like, and what it accomplishes for every child. Worse yet, the difficulties parents face in accessing quality inclusive education for their child has led many to default to segregated settings. It is not enough to simply insert children with disabilities into common classroom environments. Policy and practice changes – in individual schools, in school boards and indeed at provincial/territorial education departments – are required to facilitate quality inclusive education. With few exceptions, education policies across the country remain primarily based on the model of separate special education.

At a post-secondary level, Federal programs and funding need to accommodate and support individuals with intellectual disabilities who are pursuing continuing education opportunities.

Inclusive post-secondary education has proven to be an effective means of enabling adults with intellectual disabilities to gain knowledge and skills, pursue their interests, develop friendships, strengthen personal identity, and pursue a career upon completion of their studies.

The uneven and inadequate development of inclusive post-secondary options across the country requires a more unified national strategy to ensure that adults with intellectual disabilities have comparable opportunities to those without disabilities. There is a need to develop policies and secure funding to sustain and expand inclusive post-secondary education.

Changing the overall status of Canadians with intellectual disabilities cannot be achieved while the education system continues to segregate children on the basis of disability and deny adults with intellectual disabilities access to inclusive post-secondary education.



Diversity includes.

Supporting Families

Our Vision for Families:

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, accessible 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.
- 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.

- 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.

How Canada is measuring up

Making the grade...

- The Preamble to the CRPD recognizes that countries should provide “assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.
- There are a number of measures within both federal and provincial income tax systems that provide financial support to families to offset the additional costs of disability related supports and services (e.g. Disability Tax Credit, Medical Expense Tax Credit, Caregivers Tax Credit, Child Disability Tax Benefit).
- The Registered Disability Savings Plan (RDSP), the first of its kind in the world, assists families in securing the long-term economic stability of their relatives with severe disabilities. Positive features include Savings Bond and Savings Grant components.
- Positive amendments made to the RDSP in 2010 include a 10-year carry forward of grant and bond entitlements, and allow rollover of a deceased individual's Registered Retirement Savings Plan and Registered Retirement Income Fund proceeds into the RDSP of a financially dependent child or grandchild with a disability.
- While range, eligibility and access vary, all provinces and territories have supports and services available to families with children or adults with intellectual disabilities (i.e. respite, home supports, special equipment, etc).

Improvement still needed

- A quarter of families of children with an intellectual disability report financial difficulties in meeting household and disability-related expenses.
- 66% of parents report having had to quit/lose work, decline a job, forego a promotion, or work fewer hours.
- 60% of parents report ‘sometimes’, ‘often’, or ‘always’ having feelings of stress stemming from difficulties balancing paid and unpaid work and care responsibilities.
- In some provinces/territories extensive

Our Assessment

A strong and vibrant family is the basic unit upon which our society is built. Families are the single most important source of support and nurturing for a child with a disability to get a good start in life, and to live full and inclusive lives within community. Families of children with intellectual disabilities face the same challenges and rewards as do other families. However, caring for a child with disabilities often brings challenges and stresses that are unique compared to families with children without disabilities. It is these additional challenges for which families need support.

Families provide the bulk of supports that their family member with a disability requires. Families do not wish, nor have they asked, to have their financial or caregiving roles replaced or removed. Rather families ask for support – necessary support to ensure that their role can be fulfilled in a manner that ensures the full inclusion of their sons and daughters, in family and community; support that sustains the overall, including financial, well being of the family unit.

As the data above indicate, it is clear that far too many families do not receive the type or extent



- waitlists for child and family support services exist (e.g. in Ontario, 7,000 families looking for Special Services at Home) with unquantified waitlists in others (e.g. BC, NL).
- 73% of parents lacking the help they need report cost as the barrier.
- 37% of parents report that the services they lack are not available locally and 39% report not knowing where to find this help.

of support required. As a result, families throughout this country encounter and endure high levels of stress and experience undue and harsh economic consequences. These outcomes are created not because their son or daughter has a disability but rather because they are unable to access the supports needed. In the absence of appropriate supports and services, the family is expected to play a role well beyond that of typical parents and well beyond the childhood years. All too often this jeopardizes their social and economic well being.

Public programs and supports are a critical foundation for all families in this country, but they have not been adapted and enhanced to meet the needs of families where a child has a disability. Existing supports do not adequately address the real and known needs of families, and thus create further barriers to their well-being. A more comprehensive family supportive policy agenda, one that has both federal and provincial/territorial components, is desperately needed to address the full range of supports that families need.



Diversity includes.

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.

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.

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 and Territorial jurisdiction, we believe that disability is best understood as a citizenship issue and that there is shared responsibility among all governments 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 programs and block transfer funding mechanisms. Accordingly, the federal government now 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.

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.

How Canada is measuring up

Making the Grade

- In ratifying the CRPD, the government of Canada recognizes the relationship between disability supports and the capacity of persons with disabilities to exercise their rights as secured and articulated in the CRPD.
- The Federal Government via its Enabling Accessibility Fund supports community-based projects in improving accessibility, and removing barriers. In the 2010 Federal Budget, an additional \$45M over the next three years was announced.
- While range, eligibility and access vary, all provinces and territories provide a range of disability supports to persons with intellectual disabilities.
- Ontario has recently introduced a Services and Supports to Promote the Social Inclusion of Persons with Disabilities Act.
- While amount, eligibility and access vary, the majority of provinces and territories allow for direct or individualized funding.
- Several jurisdictions (e.g. SK, PEI, YK) have or are in process of (e.g. NS, NL) introducing Provincial Disability Strategies.

Improvement still needed

- Nearly half (45%) of people with an intellectual disability report as needing more help than they are currently receiving.
- Many jurisdictions in Canada continue to link eligibility and access to disability related supports to meeting certain financial criteria.
- Several provinces have waitlists for disability support programs (e.g. Ontario (individualized funding – 4,000, residential services – 12,000; B.C. (individual funding – 600)
- The non-refundable Disability Tax Credit designed to, at least partially, offset the cost

Our Assessment

Access to adequate and timely disability supports is the most important element in ensuring that people with intellectual disabilities have opportunity to live inclusive and meaningful lives in community. The need for these supports is present across the entire lifespan. Without disability supports many persons will not go to school, not get – or keep – a job, not live independently and ultimately not be part of their community on an equal basis with others. Disability supports are the lynchpin for meaningful inclusion.

Data presented above clearly indicate that while there is national recognition of the need for disability supports, their provision is still very sporadic, inconsistent and inadequate. In many jurisdictions services are available but not accessible; in others supports are often times simply not available. The provision of supports and services has not kept pace with demand, and, unlike health care in this country, is still largely seen as a matter of charity rather than as a fundamental right and a key to citizenship. Most disability supports are still delivered in ways in which control and decision making are vested with traditional service providers rather than more correctly with people with disabilities themselves.



of disability supports provides no benefit to those without a taxable income.

- People with intellectual disabilities report that current systems of support are too rigid and unresponsive to their individual needs, often relying on standardized assessment of extent of disability rather than determination of individual need.

Unless and until concerted effort is directed at ensuring all people with disabilities have access to responsive, flexible, portable and individualized disability supports Canada will never become the diverse and inclusive country it claims to be. If people with disabilities continue to be unable to access the supports needed, as a country we will continue to see staggering rates of poverty, and the unnecessary and unacceptable exclusion and isolation of persons with intellectual disabilities.

While the provision of disability supports falls largely within the jurisdiction of Provincial/Territorial governments, their foundational impact on realizing one's citizenship rights make disability supports a Federal issue as well. Collective efforts and a better understanding of how the federal government can contribute, in partnership with provinces and territories, to ensuring access to supports is needed. The denial of disability supports is fundamentally a denial of the opportunity, and the right, to be a contributing Canadian citizen.



Diversity includes.

Conclusion

If Canada is serious about making true and lasting change to the current status of citizens with intellectual disabilities and their families, access to quality inclusive education and appropriately funded, flexible and individualized disability supports must be top priorities. When we look broadly at the status of Canadians with intellectual disabilities we know that:

- Adults with intellectual disabilities are three times more likely than others to live in poverty;
- Almost half of working age people with intellectual disabilities are in receipt of welfare; and
- Employment rates for working-age adults with intellectual disabilities are one-third of the employment rate of people without disabilities.

These outcomes do not exist in a vacuum. Their genesis lies in excluding children with intellectual disabilities from school, preventing meaningful engagement and participation in community, and denying access to disability supports. This means that as children grow into youth and transition to adult life, they cannot get training and opportunity to get – and keep – a job and develop a career. If proactively and comprehensively addressed, full access to inclusive education and disability supports could reshape the experience of disability in this country.



Bendina Miller, President of the Canadian Association for Community Living, and Caroline Matte of LiveWorkPlay at the release of the 2009 CACL National Report Card.

Simply put, adults with intellectual disabilities who are well supported and educated are more likely to have jobs and less likely to live in poverty. This is not a complex equation. The formula to achieve this outcome is well known. It requires multifaceted solutions, collaboration among all levels of government, and supports and services that are responsive, flexible and individualized. It requires coming face-to-face with Canadians with intellectual disabilities, accepting that, for the most part, what we have been doing isn't working, and having the courage to change course.

We need a new story of disability in Canada. It is time to think bigger when we think diversity, and celebrate and welcome disability in our lives and communities. As a country, we must reject the notion that disability inevitably results in poverty and isolation; and demand instead, that people with intellectual disabilities and their families access supports and opportunities to engage in this country as full and valued citizens.

Beginning in 2007, CACL has issued an Annual National Report Card to track and report on progress we are making as a country in achieving the full inclusion of persons with intellectual disabilities. This 2010 Report Card presents data on three of our objectives – Inclusive Education, Supporting Families and Disability Supports. A full Report Card (as was issued in 2008) that addresses progress in all 10 objectives is issued every five years. Data sources for this Report Card include PALS 2006 and information from PTACLs.