

inclusion of Canadians with intellectual disabilities



The Canadian Association for Community Living (CACL) has a bold vision for the future. A Vision for a Canada in which all persons with an intellectual disability are fully and meaningfully included in community, in family, and in all the typical activities of everyday life.

We envision a future where disability is viewed as just one more aspect of our natural diversity. A future where our society provides the necessary supports and services so that persons with an intellectual disability and their families can participate and contribute. A future in which the myriad of existing barriers to full inclusion have been addressed and removed. We see this future, not as a benign response for a charitable cause, but rather as a right of citizenship. A Right that should not, and cannot, be further denied to the more than 750,000 of our fellow citizens with intellectual disabilities.

This future must start now. It is a future that builds on the achievements that we have attained in this country over the past 50 years, but also a future that acknowledges that these achievements still fall far short. Our future must begin

with a recognition that for an unacceptable number of people, the experience of disability is still one of exclusion, isolation and poverty.

To guide us toward this future, CACL has adopted the following ten-point, ten-year Agenda:

- 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***

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

All Canadians hold for themselves a vision of life in community. In a home where we want to be, somewhere we feel comfortable, safe and in control; a place that provides personal space, and where we can enjoy family and friends. A home that roots us in community and adds to our identity. 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”.

Benchmarks to measure progress

1. Further admissions to large institutions are halted.
2. All large institutions for people with intellectual disabilities are closed.
3. People are not inappropriately living in other institutional settings like nursing homes, etc.

'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.'

— PFC CACL Task Force on Deinstitutionalization

4. All supportive living options are based on choice, self-determination, and individualized funding.
5. People with intellectual disabilities have equal access to the range of adequate and affordable housing generally available in their community.

How Canada is measuring up

Making the Grade...

- Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, which Canada has signed, secures for the first time in international law, a right to live in the community.
- Ontario closed its remaining three large government operated institutions for persons with intellectual disabilities.
- There are only three large institutions (larger than 100 beds) for persons with intellectual disabilities in Canada – Valley View Centre (SK), Michener Centre (AB) and Manitoba Development Centre (MB) compared to 31 such facilities in 1986.
- The government of Saskatchewan announced (in 2008) the investment of a four-year, \$76.9 million initiative to eliminate the waitlist for residential and day-program services for people with intellectual disabilities.
- The government of New Brunswick has given approval for the replacement of the Restigouche Hospital Centre. It is expected that persons with intellectual disabilities currently living in this facility will be assisted to move into the community over the next two years.

Improvements still needed

- Governments in Manitoba, Saskatchewan, Nova Scotia and Alberta have not indicated any plan to close their remaining institutional facilities.
- There are still more than 900 persons with intellectual disabilities living in large institutional facilities.

- The province of Nova Scotia continues to view institutional placements as acceptable for persons with intellectual disabilities, and in 2009 created 19 new institutional placements.
- At least eight provinces continue to use facilities with more than 9 beds as a housing option for persons with intellectual disabilities. Comprehensive data as to the total number of these facilities and the resident population is not available in the public domain.
- Thousands of persons with intellectual disabilities are currently housed in other facilities such as nursing/seniors homes,



personal care homes and long term-care facilities.

- In 2009, 19 cases of abuse against residents at the Riverview Adult Residential Centre in Riverton, Nova Scotia, were disclosed, with 22 other cases of reported abuse at other institutions throughout the province.

I am 39 years old and living in this institution for old people. I should not be here, right? I want to leave.

Our Assessment

The closure of the last remaining large government operated institutions for persons with intellectual disabilities in Ontario was a major achievement. The culmination of a 20 year commitment, these successful closures demonstrated real vision and leadership on the part of Ontario and gave further evidence to the assertion that in Canada we do not need to rely on large institutional facilities as a response to the housing needs of persons with intellectual disabilities.

Despite the recent leadership of Ontario, the successful closures of large institutions in other provinces, and research confirming that persons with intellectual disabilities are not best served in large institutions, Alberta, Saskatchewan and Manitoba continue to operate and rationalize their remaining institutions.

Deinstitutionalization is a process that involves providing the necessary supports and services in the community so that persons with intellectual disabilities are able to exercise choice and control in where they live and with whom. Unfortunately the trend in this country is still heavily weighted toward creating and funding

traditional 'residential options', and thus we continue to witness the proliferation of the 6, 8, and 10 bed group home model. While clearly an improvement in comparison to a 200 – 300 bed institution, these homes still represent a placement model rather than one in which persons have full choice and control.

Perhaps most alarming, we continue to witness persons with intellectual disabilities being placed in other institutional environments such as Nursing Homes, Personal Care Homes and Seniors Residences. These are clearly not options of first choice for persons with intellectual disabilities (or their families) but in far too many instances are the only options offered.

If adequacy and availability of appropriate housing are indicators of success then we have yet to achieve a passing grade. If choice and control over where one lives are fundamental rights of citizenship then significant improvements remain to be made.



Diversity includes.

Eradicating Poverty

Our Vision:

Eradicate poverty for people with intellectual disabilities and their families

Canadians with intellectual disabilities have the income and resources they need to secure a good quality of life and fully participate in all aspects of their communities.

Why this Vision

Canadians with intellectual disabilities are more likely to live in poverty than other Canadians – it has been estimated that almost 75% of adults with intellectual disabilities not living with family members live in poverty. As long as people with intellectual disabilities continue to be excluded from the labour market there will be an over-reliance on social assistance as the primary source of income. All too often these income support systems are inadequate and stigmatizing. Without adequate access to disability supports people are unable to maintain an adequate standard of living through paid employment. Income derived from employment is often clawed back. As a result, many people are forced to rely on income security programs. Built as a system of last resort, social assistance systems have become a system of first resort for Canadians with intellectual disabilities.

Benchmarks to measure progress

1. The poverty rate of children and adults with intellectual disabilities will not be higher than those of the corresponding general population.
2. People with intellectual disabilities, families, and other people who provide support do not incur non-reimbursed expenses related to disability.

How Canada is measuring up

Making the Grade...

- The availability of guaranteed income (i.e. Old Age Security plus the Guaranteed Income Supplement) has a significant impact on minimizing the differential in the poverty rates between seniors with disabilities and seniors without disabilities.
- The Government of Saskatchewan has introduced the Saskatchewan Assured Income for Disability (SAID) Program as of November 2009.
- Several jurisdictions (e.g. Newfoundland and Labrador, New Brunswick, Manitoba, Quebec and Ontario) have provincial Poverty Reduction Strategies, components of which provide specific actions relative to persons with disabilities.
- The Parliamentary Committee on Human Resources, Skills Development and the Status of Persons with Disabilities is completing a study on the role of the federal government in addressing the poverty of Canadians.
- The Senate Committee on Social Affairs, Science and Technology is completing a study on poverty, housing and homelessness in Canadian cities.

People don't treat me with respect and dignity because I am poor. We need a social assistance program that helps me, not punishes me.

Improvements still needed

- Of working-age persons (15-64 years) with intellectual disabilities who live alone, 73.2% live below the poverty line compared to 23.3% of working-age Canadians without disabilities who live alone.
- Overall, working-age persons with intellectual disabilities are almost three times more likely than working-age Canadians without disabilities to be living in poverty.

I don't want to inflict my poverty onto someone else.

Our Assessment

Poverty remains an outcome for an unacceptably high percentage of Canadians with intellectual disabilities. This poverty is a result of an intersection of a number of complex issues. An over-reliance on an inadequate income support system is but one of these factors. Others include significant and ongoing barriers to inclusive education, post secondary educational and technical training, and inability to access needed disability related supports. Often attainment of employment comes at the expense of becoming ineligible for needed health care coverage, personal and attendant care (items usually covered while in receipt of income support). The net effect for many is that they are financially 'better off' on welfare.

This abject and pervasive poverty level is not an issue that can be addressed and resolved at the individual level. It is not simply a matter of 'finding a job'. It cannot be viewed simply as a personal failure. Rather it must be more correctly seen as a failure of our systems to appropriately and adequately support people to secure adequate and dignified means of



- 45.5% of working-age people with an intellectual disability indicate they receive provincial / territorial social assistance.

support. Significant disincentives still exist that create and maintain a reliance on income support as a primary source of income for many people with intellectual disabilities.

This outcome is not surprising when we consider that persons are excluded from education and training opportunities and denied the supports they need to go to school, get a job and keep a job. It is inexcusable in a prosperous country like Canada that the most likely outcome for persons with intellectual disabilities is one of poverty. The implementation of Poverty Reduction Strategies and the creation of a separate and enhanced income support program for persons with disabilities are encouraging developments but as of yet insufficient to address this national disgrace.

We believe it is urgent for the government of Canada to confront the income gap for Canadians with disabilities, and especially for those with significant disabilities whose prospects for earned income are extremely limited.



Diversity includes.

Achieving Employment Equality

Our Vision:

Achieve employment equality

Working-age adults with intellectual disabilities are employed at the same rate as the general population.

Why this Vision

Work is a very important part of our adult lives. Employment is much more than simply earning money. Through paid employment we meet new people and establish new friendships, increase feelings of self worth, enable greater independence, become part of our community and contribute to our society and economy. Perhaps more importantly it affects how other people and society in general view us — attributing feelings of value, contribution, ability and capacity.

Unfortunately, employment opportunities remain closed to most persons with intellectual disabilities. Policy and program factors create layers of disadvantage and multiple barriers to employment. Even today, it means overcoming negative employer attitudes and misperceptions. Often it means being financially worse off (after covering costs of disability related supports) than remaining out of the labour force.

We're still being punished for going to work. When I go to work I get to keep only \$150 of what I earn. If I earn more I lose my health care card and my rent increases. By going to work I lose money - this just doesn't make any sense to me.

Benchmarks to measure progress

1. Employment rates for people with intellectual disabilities are equal to that of the national average.
2. People with intellectual disabilities do not face financial or other disincentives to seek and maintain employment.

3. Employers are taking leadership in advancing the employment of people with intellectual disabilities.
4. People with intellectual disabilities and employers have the supports needed to establish and maintain inclusive workplaces.
5. People with intellectual disabilities are equally represented in both unionized workplaces and non-unionized workplaces.

How Canada is measuring up

Making the Grade...

On a national level, data with respect to the employment of persons with intellectual disabilities reveal a situation that is both disturbing and unacceptable. Despite long standing efforts at both the federal and provincial levels directed at enhancing the employment of persons with intellectual disabilities, through such mechanisms as the Labour Market Agreements for Persons with Disabilities, Opportunities Fund, Employment Equity, etc., no substantive overall improvements have been noted. This finding stands in stark contrast to the fact that there is clear and irrefutable evidence that persons with intellectual disabilities, when supported, can be and are gainfully employed in meaningful jobs. Data would support a contention that unless our strategy and approach to this issue changes significantly we will not witness real improvement in this area.

Improvements still needed

- The employment rate for working-age adults with an intellectual disability is only one-third of the employment rate of people without a disability (25.5% compared to 75.5%).
- The average income for working age persons with an intellectual disability who are working is less than half of that of Canadians without a disability.

- Less than one in five working-age adults with an intellectual disability work more than 49 weeks in a year (either full or part time).
- Significant numbers of adults with intellectual disabilities remain enrolled in segregated day programs/workshops.
- Anecdotal evidence obtained from families indicates that the transitional planning process in secondary schools is inadequate in preparing their sons/daughters for the world of work.

Because of clawbacks, going to work is worse than staying on welfare.

Our Assessment

We know from both research and personal stories that persons with intellectual disabilities are able to and indeed want to work. Yet after decades of concentrated efforts on increasing the employment of adults with intellectual disabilities, less than one-in-five are employed. Clearly this dismal outcome must call for a reassessment of our strategies and efforts. Surely it is possible to connect a workforce that is ready to go to work with a labour market that is in need of workers.

Preparation for and placement in the workforce is simply not adequate or effective for working-age adults with intellectual disabilities in Canada. Increased attention must be given to the provision of needed on the job supports, as well as a consideration of the impact of employment on the other aspects of the individual's life (e.g. eligibility for health care coverage, subsidized housing, earnings exemptions, etc). Research demonstrates that when people have access to decent education and training, access to employment supports and access to transportation – the result is meaningful and sustained employment.



- In many provinces and territories, on-the-job support (such as co-worker support) is often times of insufficient duration to enable a successful transition to and maintenance of long-term employment.

The harsh reality in this country is that a very large percentage of persons with intellectual disabilities remain reliant on provincial/territorial income support systems that leave recipients living below the poverty line. These systems were never designed nor intended to be used as a primary or enduring source of income. Paradoxically, even with the minimal benefits that social assistance provides, for many, a transition to paid employment often results in a financial loss. The issue and answer is whether we are prepared to undertake the kind of transformative action needed that will ensure a financial benefit to the individual. We must be prepared to introduce significant changes to social assistance programs that would allow people to keep more of their earned income, combined with a comprehensive program of ongoing disability supports for employment. Only then can we realistically expect to have significant positive impact on the employment rates of persons with intellectual disabilities.



Diversity includes.

Conclusion

The data provided in this Report Card as related to the objectives of Closing Institutions, Eradicating Poverty, and Achieving Employment Equality reveal a significant gap between our vision and our reality. Our vision is for a Canada in which all persons with intellectual disabilities live in community as equal citizens, as members of the workforce with adequate resources to participate fully and freely in their society. This vision stands in stark contrast to the current reality where so many continue to be institutionalized, unemployed, without adequate income and, as a consequence, living in the grip of poverty.

We continue to keep people in institutions when we know that even persons with the most significant of disabilities can and are living in community. We continue to systematically encourage people to remain in sheltered workshops and/or in receipt of welfare when we know that with appropriate supports people with intellectual disabilities can and are gainfully employed. We continue to create poverty as an inevitable outcome of having a disability when we know that other outcomes are possible.

Our understanding of disability has changed considerably in the past 50 years. We now understand that disability is not caused as much by individual factors as it is the net effect of social, economic and physical barriers and lack

of needed supports. The majority of Canadians value a society in which persons with disabilities are supported to exercise fully their rights as citizens. However the bulk of our systems and structures continue to be designed and delivered based on outdated and inaccurate assumptions and values about people with intellectual disabilities. While our values and expectations are changing, the rules have not.

Inclusive outcomes for persons with intellectual disabilities remain an exception rather than a typical expectation. A new approach is required to make our vision of a fully inclusive Canada a reality for all Canadians – an approach that supports and entrenches the participation of persons with intellectual disabilities. An approach that recognizes that the bulk of our current systems and structures impede rather than advance inclusion. Currently, a life of inclusion is enjoyed only by a minority of persons with intellectual disabilities. A new approach must ensure this outcome for all. This transformation will require leadership and innovation by government – both at the national and provincial / territorial levels. It will require the full participation and resolve of families, persons with intellectual disabilities, community organizations and service providers. Ultimately it requires the full support and endorsement of all Canadians.

2009 Report Card

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 2009 Report Card presents data on three of our objectives – Deinstitutionalization, Income and Employment. A full Report Card (as was issued in 2008) that addresses progress in all 10 objectives is issued every five years.

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