

inclusion of Canadians with intellectual disabilities



a national report card
2013



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Diversity Includes.

The life situation of most people with intellectual disabilities (and their families) is much different, and certainly more positive, today than it was 60 years ago when our Association first began its advocacy efforts. In those 60 years we have witnessed incredible advances in securing and protecting the right of people with intellectual disabilities to live and participate in community, as full citizens. Rights that are now entrenched and guaranteed within our Charter of Rights and Freedoms, and most recently reaffirmed within the UN Convention on the Rights of Persons with Disabilities.

However, despite these significant advances we still witness far too many instances of people with intellectual disabilities being excluded—from community, from employment, from school—and unfortunately are now witnessing growing distress and concern within families. Families who are unable to access the type and extent of supports needed to ensure their sons and daughters are fully included within family, or the supports needed so that they can establish an inclusive life outside the family home. So life for many has improved, but for some it is no better, perhaps worse.

This is not a time for complacency. It is a time when we must be even more vigilant and vocal in our efforts to ensure that every person with an intellectual disability and every family has the support they need to be full citizens and to enjoy, equally, the benefits of being Canadian.

A Report Card on Inclusion

The Canadian Association for Community Living (CACL) has a vision for this country in which Canadians with intellectual disabilities are full participating citizens. A vision of equal citizenship—of citizenship that brings with it the same rights and freedoms guaranteed to all Canadians. A vision of a country in which disability is viewed not as something to be avoided but rather embraced as a natural part of our diversity. It is a vision founded in the legitimate expectations of Canadians with intellectual disabilities and their families. A vision that we must all collectively work toward making a reality for all Canadians with intellectual disabilities.

CACL's Vision 2020

CACL has adopted the following ten point agenda to guide Canadians and our governments in building a more inclusive Canada for tomorrow. 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*

To achieve this vision, Canadians must know where we are today and where we are going. The National Report Card on Inclusion tracks and assesses progress towards the attainment of these objectives. This 2013 Report Card examines how we, as a country, measure up on two of these 10 objectives: Ensure Families have Needed Support, and Achieving Employment Equality.

Data for this report card was drawn from a variety of sources, including the CACL online Employment survey 2013, reports by Statistics Canada, Health Canada, the Public Health Agency of Canada, various governmental reports and journal articles.

Ensure families have needed supports

Our Vision for Families

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. 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:

1. Families have access to needed supports and services to meet the needs of their family (i.e. respite, in-home support, and home modifications).
2. 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.
3. 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.

4. 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 United Nations Convention on the Rights of Persons with Disabilities, which Canada has ratified, recognizes that countries should provide “assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.
- Measures within the income tax system provide financial support to offset the additional costs of disability. These include the Disability Tax Credit, Medical Expense Tax Credit, Caregivers Tax Credit, Child Disability Tax Benefit, Compassionate Care leave, Income Splitting provisions, enhancements to the Registered Disability Savings Plan (RDSP) and the recently announced exemption from Goods and Services Tax/Harmonized Sales Tax (GST/HST) for personal care services for individuals who require such assistance at home.



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Improvements still needed...

- More than one in five parents (22%) who provide support to a son or daughter because of disability or a health condition are doing so because that child has an intellectual (developmental) disability.
- Half (51%) of people who provide informal support to a family member or friend with intellectual disabilities provide ten or more hours of support per week. Many experience emotional distress and poorer overall health than others. Many also experience difficulties coordinating care and need more supports so they can have time for other family responsibilities and for personal activities.
- 60 per cent of Canadian family caregivers pay out-of-pocket expenses (primarily transportation and medication-related costs), with 30 per cent spending over \$300 per month.
- No PT jurisdiction was able to provide accurate data as to the number and/or percentage of children with intellectual disabilities in care within its child welfare system, although research has indicated that the numbers and percentages are very high in some jurisdictions.
- Extensive waitlists for child and family support services exist in Ontario, Nova Scotia, Quebec and BC. Other jurisdictions do not maintain wait lists or say there is no waiting.

Our Assessment

While there is an array of supports and services provided to and on behalf of persons with intellectual disabilities by governments and community agencies, there is no denying that families are the backbone of the 'disability supports system' in Canada. Support provided by families is without remuneration or compensation, and while freely given, the provision of such support does not come without a price. For many families it means a lessened ability to participate in the labour force, an expectation to play a parenting role well after the typical childhood years and usually increased financial costs beyond those typically associated with raising a child.

Many families face significant and serious challenges on a daily basis. Challenges that jeopardize their ability to support their sons and daughters to live inclusive lives within the family unit. Similarly lack of appropriate supports often forces continued residence in the family home, long after desired by either the family or the individual with intellectual disabilities, often times to the point of crisis.

The current system of supports falls well short of providing the type and extent of support needed by families. Supports are needed, not to replace family involvement, but rather to supplement and assist. Families need supports that address the needs of families, recognizing that these are often separate and distinct from that needed by their family member with an intellectual disability. Families need respite, supports that will enable their full participation in community and in the labour force, and support that will lessen the financial challenges that are often associated with raising a child with intellectual disabilities.

Families are committed to ensuring that their sons and daughters are fully included within community, from childhood into adulthood. What they most require is additional support to enable that to happen. At this time, more than ever, we need a comprehensive family supportive policy agenda, at both the federal and provincial/territorial level that will address the full range of supports that families need.

Achieving Employment Equality

Our Vision

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 work we meet new people and establish new friendships, increase feelings of self worth, enable greater independence, become part of community and contribute to that community. 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. Often 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.

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 is Canada measuring up

Making the Grade...

- Research shows that most employers who hire people with intellectual disabilities have positive experiences and would hire them again.
- Research based on large government data sets have found a net benefit for each public dollar spent on the supported employment of people with intellectual disabilities.
- Results from a CACL online survey reveal that most people with intellectual disabilities who aren't working want to be working and that most who have a job enjoy their work "a lot".
- The 2013 Federal Budget committed to introduce a new generation of Labour Market Agreements for Persons with Disabilities to better meet the employment needs of Canadian businesses and improve the employment prospects of persons with disabilities.
- The 2013 Federal Budget proposed an increase to the Opportunities Fund for Persons with Disabilities and to involve employers and community organizations in the design and delivery of projects.



Diversity includes.

- The Government of Canada has created the Canadian Employers Disability Forum to “facilitate education, training and sharing of resources and best practices concerning the hiring and retention of persons with disabilities.”
- The Government of Canada, as well as provincial and territorial governments, are increasingly making the link between the inclusion of people with disabilities in the workforce and increased economic productivity for all.

Improvements still needed...

- The employment rate for working-age adults with an intellectual disability is only 25%, which is half that of people with other disabilities (50%) and one-third of the rate of people without a disability (75%).
- Early results from the CACL survey confirm other research that shows significant unmet needs of people with intellectual disabilities for

Our Assessment

The employment rate of persons with intellectual disabilities in Canada is quite simply unacceptable. Despite decades of efforts, and in full acknowledgement of the wide array of measures that exist at both the federal and provincial/territorial levels, 3 out of every 4 Canadians with intellectual disabilities remains unemployed! More alarming still, many thousands of people with intellectual disabilities remain trapped within segregated and congregated day programs that while promising training and job preparation, rarely deliver on that promise. Clearly a different strategy and approach is needed if we are to witness real improvement in this area.

Research and personal stories clearly demonstrate that persons with intellectual disabilities are able to and indeed want to work. When supported, they can be and are gainfully employed in meaningful jobs. Employers who hire persons with intellectual

help from someone on the job and for modified job duties and work schedules.

- When asked about how employment for people with intellectual disabilities looks now compared with five years ago, the CACL survey reveals only one in six people who say it has gotten better. About 4 in 10 say things look about the same and about a quarter say things have gotten worse.
- The main approach to daytime support for thousands of people with intellectual disabilities remains sheltered workshops and segregated day programs. Many in these programs earn less than minimum wage.
- There are no reliable data on the percentage of persons with intellectual disabilities on PT social assistance caseloads. However, persons with some level of disability make up 30% to 60% in the 6 jurisdictions that were able to provide any data on these issues.

disabilities speak positively of their value as employees and their contribution to the workplace. Yet most employers fail to recognize the potential value in hiring people with intellectual disabilities, and certainly do not view them as a pool of potential employees.

If we are truly to make an impact on the employment rate of persons with intellectual disabilities then we must become more active in our efforts to help employers understand that people with intellectual disabilities represent a hugely untapped labour pool of motivated and competent individuals who could greatly assist in successfully meeting their labour force needs.

UN Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD positions disability as a human rights issue, rather than a social welfare concern, and contextualizes disability within a progressive social model. It does not create any 'new rights' but expresses existing rights in a manner that addresses the needs and situation of persons with disabilities. In so doing, it provides a deeper understanding of disability and what is required to ensure that the rights of persons with disabilities are fully realized. The CRPD promotes, protects and ensures the full and equal enjoyment of all human rights by persons with disabilities.

Supporting Families

The CRPD recognizes the family unit as playing a pivotal role in the realization of rights of persons with disabilities. The Preamble, in section (x), states that "the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protections and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities."

Another relevant article in the CRPD is Article 23: Respect for home and the family. This Article states that "State parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others"

Employment

The CRPD recognizes the right to work and employment in Article 27: "States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including legislation..."

Particularly relevant sections of Article 27 would have governments: (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions; (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training; (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment; (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures; and (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace.

The full text of the Convention can be viewed at:
<http://www.un.org/disabilities/convention/conventionfull.shtml>



Diversity includes.

Conclusions

This report card supports two basic conclusions. Firstly, families continue to have many unmet needs and face significant challenges in providing support to their sons / daughters with intellectual disabilities, while at the same time trying to balance other work/life commitments. Secondly, working aged adults with intellectual disabilities remain greatly underrepresented in Canada's workforce.

Families provide an essential bridge to the realization of citizenship and to advancing the full inclusion of their family members with disabilities. Within the family context, children with intellectual disabilities form the connections and relationships with community that will be so essential to a lifetime of inclusion and participation. The crucial role of family is something that cannot be replaced or minimized. But it is also a role that must be supplemented by additional support for those who need it.

Without adequate support, families supporting a family member with an intellectual disability are often more likely to: face exclusion from the labour market; have a more difficult time keeping their jobs; and experience increased out-of pocket expenses for their family members. Too many live in poverty. It is typically women—mothers—who bear the full brunt of these challenges.

Due to the absence of needed community supports, parents are increasingly being called upon to extend their direct parenting role well beyond that expected for sons/daughters without a disability. As eligibility criteria are tightened and waiting lists grow, parents report that accessing needed supports for their sons and daughters is becoming increasingly difficult. We know that people with intellectual disabilities can lead full, inclusive and participatory lives in community, and that strong healthy families are key to achieving that reality. Increased investment is required of all levels of government to acknowledge



and nurture the invaluable role played by families. Families require—and deserve—better, more flexible supports.

The continued exclusion of working aged Canadians with intellectual disabilities from the workforce is shameful, wasteful and unnecessary. At a time when most employers are experiencing a crisis in recruitment and retention, many thousands of adults with intellectual disabilities—adults who are ready, willing and able to go to work—remain out of work. The current employment 'system', and associated support structures, is simply not meeting the needs of individuals with intellectual disabilities or the needs of many potential employers. It is often based on an assumption of non-employment and reliance on workshops and day programs rather than inclusive, competitive employment. The current system is part of the problem. A new approach is needed. One that is innovative, empowering, responsive and takes an 'employment first' approach. An approach is needed that places greater emphasis on meeting employer demand and contributes to the modernization of the community support system. One whose first and preferred outcome will be "real jobs with real wages".