

coming together

...to create change

Spring 2010

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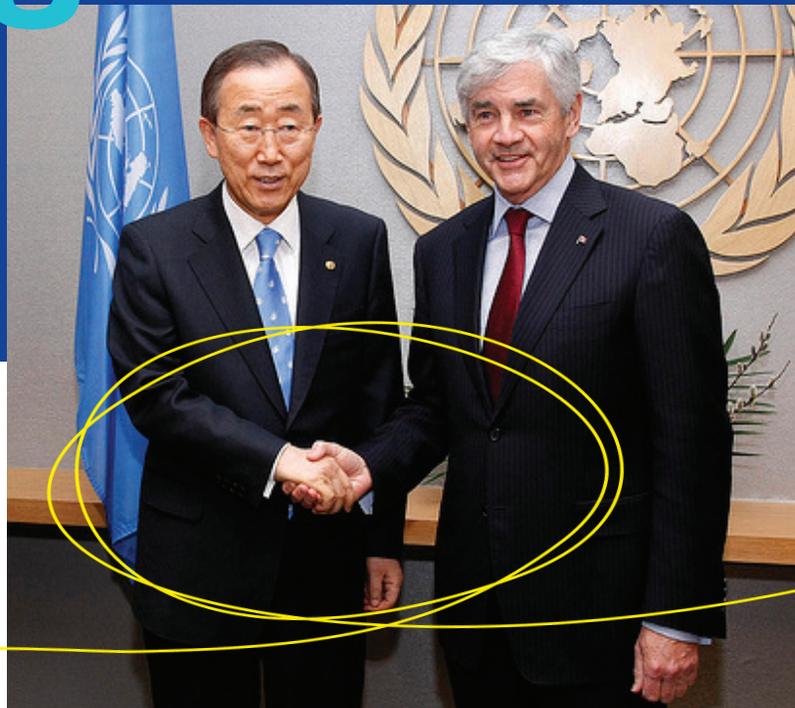
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Minister Cannon met UN
Secretary-General Ban
Ki-moon, at the United
Nations headquarters
in New York.



Canada Ratifies the UN Convention on the Rights of Persons with Disabilities!

On March 11, 2010, with the support of all provinces and territories, the Government of Canada ratified the UN Convention on the Rights of Persons with Disabilities at a ceremony at the United Nations headquarters in New York City. In honour of this historic event we are dedicating this edition of our newsletter to the Convention.

Many families are unaware of the Convention — what it means, what it does, what potential it has. They are too busy dealing with the effects of their son’s and daughter’s rights not being respected and upheld. Every day families across this country struggle to have their children included as full citizens in all areas of community life — from schools to workplaces and beyond. Any talk of an international treaty seems too far removed from their day to day reality to merit much attention.

The Convention does however provide a new tool for families to use so it is important for us to know about it and understand the potential that now exists

— a potential that has yet to be fully realized.

In this edition of our newsletter, Anna MacQuarrie of CACL, who has been involved with the Convention for many years, from the early days of its development through to ratification, will provide us with information on what it all means. Families from across the country have also provided their insight into how they see this making a difference in their lives. We also have an example of a family who has been instrumental in making this historic achievement possible.

As will be pointed out by several people in this newsletter we are not done yet! Ratification is just another step — albeit a huge one — on the path towards achieving full human rights for all individuals with intellectual disabilities — both on paper and in reality. It is more important than ever that we come together now and ensure that we continue to take the remaining steps down that path and to reach our goal sooner rather than later. It is up to us all to make that happen. The Convention is only a tool, to have impact we have to use it!



50 years
Canadian
Association for
Community Living

Diversity includes.

Message from the President of Community Living Manitoba

Members of the National Action Committee on Family Leadership and Grassroots Engagement

Nancy Armstrong – Co-chair, NB
Laurie Larson – Co-chair, CACL
Julie Smith – PEI
Shauna Henry – NWT
Mimi Kennedy – NWT
Kevin McTavish – SK
Dawn Gates – MB
Rose Flaig – MB
Beth French – ON
Tara Brinston – Secretariat, NB

The Council of the Federation

The Council of the Federation is the forum for bringing the broad Community Living Federation together to work collaboratively on advancing the full inclusion of people with intellectual disabilities and their families.

It is comprised of CACL and each of the 13 Provincial/Territorial Associations for Community Living. Through National Action Committees, members of the Council come together to share and exchange knowledge, to link existing efforts and to identify ways of working together to achieve our shared 10 point agenda.

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Cover photo and page 3 photo courtesy of Department of Foreign Affairs and International Trade



Val Surbey

President, Community Living Manitoba

In Manitoba, our provincial ACL has long recognized that one of the primary needs of families is to interact in meaningful ways with other families and that membership in a traditional ACL is not the only (or even preferred) way by which families indicate their support for the vision and goals of the broader community living movement. The renewed focus within our national federation to engage our grassroots by reaching out to families wherever they may be (family networks, parent groups etc.) is both welcomed and supported by Community Living Manitoba. We are also most pleased to participate on the National Action Committee on Family Leadership and Grassroots Engagement. We view this Committee as having great potential in providing leadership as we develop and more fully advance a national strategy.

At a provincial level, one of the many events we hold is an annual Parent Leadership Retreat. Through this event we have learned that families become stronger when they have social connections with people in similar situations, opportunities to recharge and refocus and have access to relevant and readily available information. Families need to know and be assured that they are not alone, that there is hope, that raising a child with a disability may be daunting but is certainly not

insurmountable. Families gain from the power of shared personal experiences.

Our board and committee members are committed to engaging in new ways of connecting with families. For example, our bi-weekly support circle for Aboriginal women raising children with disabilities has been hugely successful. We have no specific membership... just whoever feels the need and is able to attend. Each time the numbers vary, but it is safe to say the group is increasing and definitely illustrates a need.

Community Living Manitoba passed a motion at our last AGM committing ourselves to the priority of family leadership and grassroots engagement. With the recent ratification of the UN Convention and the possibilities that this presents, it is important to have the involvement of strong and empowered families. Our federation has a past that was built on the strength and leadership of families — we believe that if we are to have an equally successful future then we must all continue to reach out to and engage families throughout this country. Community Living Manitoba is committed to working in partnership with our national and PT partners to achieve strengthened and renewed family leadership within our federation.

Val Surbey

UN Convention on the Rights of Persons with Disabilities: An agent for change or status quo?



Anna MacQuarrie

Director, Policy and Programs,
CACL

On March 11, 2010, Canada ratified the historic United Nations Convention on the Rights of Persons with Disabilities (CRPD). Across the country, Canadians cheered the news of Canada's ratification — the legal step that binds Canada to the rights secured in the CRPD. The Canadian Association for Community Living (CACL) was present for the ratification ceremony in New York at the UN Headquarters and CACL's president, Bendina Miller, participated in a press conference with other disability activists — Steve Estey and Traci Walters — and Canada's Minister of Foreign Affairs, the Honourable Lawrence Cannon.

Canadians with disabilities, their families and disability organizations have been working towards this moment for almost nine years and there is much to celebrate. The CRPD is the first legally binding international treaty that specifically addresses the rights of persons with disabilities. It is the biggest advancement in international human rights protection and promotion for people with disabilities in history.

While March 11, 2010 was a moment to pause and celebrate the accomplishments of the CRPD and Canada's ratification, it also marked the beginning of a new phase: implementing the CRPD and making it real and meaningful in the lives of people with disabilities and their families.

Traditionally, human rights treaties seem far removed from our daily lives. We all know that in practice, the existence of a right has not always meant the enjoyment of a right — particularly for people with disabilities and their families. We all know too well the struggles individuals and families face in accessing education, employment, or a valued place in the community. Many have become skeptical of how a human rights framework makes a difference on the ground.

Will the CRPD be different? The simple answer is yes. In fact, the CRPD already is different. It is the first human rights treaty to be directly informed and influenced by the lived experience of people with disabilities and their families. It is a treaty that recognized early in its development that to be truly successful it could not merely be a lofty set of goals and principals. Further, it is a treaty that knew a re-listing of rights without understanding or addressing the barriers and obstacles that prevent realization of our rights gets us no further ahead.

The CRPD establishes no new rights but articulates what existing human rights mean in a disability context. By addressing what is necessary to make existing rights real for people with disabilities, the CRPD introduces and secures new concepts — like the right to live in the community; the right to use support to make decisions; the right to an inclusive education; and the recognition of the valuable role

The Canadian delegation addresses the media. From left to right: Traci Walters, National Director, Independent Living Canada, Lawrence Cannon, Canada's Minister of Foreign Affairs, Bendina Miller, President, Canadian Association for Community Living, and Steven Estey, Chair of the International Development Committee Council of Canadians with Disabilities.

that families play in the lives of their family members with a disability. It goes beyond a simple listing of these rights to outline the supports and services needed to realize a particular right.

As a result, the CRPD provides us with a road map that explains where, why and how the rights of people with disabilities have been neglected and what steps are required to realize human rights for people with disabilities in meaningful ways.

It is different enough to resonate with individuals and families? Yes. The way the CRPD was developed has shifted the players — or the protagonists — of human rights law. UN treaties and international human rights law often, and quite reasonably, have been the domain of lawyers and legal minds. With the development of the CRPD, we saw both in theory and practice that this Convention did not belong exclusively in the legal domain. People with disabilities and their families were seen and valued as experts in their lives and the realization of their rights.

The CRPD tells a story of how to make rights real and meaningful
Continued on back page



Diversity includes.

Reflections on a long journey

Audrey Cole
Smith Falls, ON

For my family, like many families, the adoption of the Convention by the UN was a significant event. The inclusion within the Convention of Article 12 which opens the international, legal door to what has come to be known as “supported decision making,” was and is particularly important to us. It provides our family with a glimpse of what, in the not too distant future, could be the culmination of a 40 years long effort to ensure that our son will never be placed under guardianship.

It seems a bit ridiculous that I would have been worrying about adult guardianship when Ian was only about six but it wasn't Ian, himself, who got me hooked on my long anti-guardianship crusade: it was something I read. Ian's dad is a former senior Librarian who spent his entire professional life in the Library of what was then Canada's Department of National Health and Welfare. Fred was a whizz at finding written materials relating to disability and to people with disabilities. I have talked elsewhere of arriving home from the hospital with a new born Ian to find the coffee table already loaded with “must read” books,

learned papers and leaflets! Fred was the eternal information “finder!” With the wealth of spare time every new Mum has in those early days of motherhood, it was my job to be the “reader and absorber!” This, by the way, continues to be the pattern! It seems to work!

It was in late 1969 that a red booklet appeared on the coffee table. Published by the then nine-year-old International League of Societies for the Mentally Handicapped (now known and revered as Inclusion International), the booklet contained the conclusions of the *Symposium on Guardianship of the Mentally Retarded*. The symposium had been held in San Sebastian, Spain, earlier that year. Representing CACL in those deliberations was a young Barry Swadron, now a well-known and highly regarded Toronto based human rights lawyer (who, a few years later, in 1972, also authored a book, *Mental Retardation, The Law, Guardianship*).

What caught my attention all those years ago in the San Sebastian findings was the clear recognition by organizations such as ours that guardianship did not serve people with intellectual disabilities well, that it needed “revitalization.” What I took from the deliberations was that we required mechanisms that, literally, would keep the options open for people with disabilities as they gained confidence from new experiences in the broader and gradually more welcoming community. Guardianship, as we knew it, could not do that. Obviously, there had to be a more fluid approach to protection. Always a bit of a radical, that sounded good to me!

Guardianship would not be what we would ever seek for Ian; there had to be something more relevant to his future needs no matter what they might be. I continued to read whatever I (or Fred) could find on the issue. But Ian was six and there were more immediate demands on our time, such as Ian's exclusion from school. The perils of guardianship went onto my emotional and functional back burner; they simmered, there, nevertheless.

They boiled over at the trial of the issue of the mental incompetency of Justin Clark, in November 1982, in the County Court House in Perth, Ontario. Ian was 17. At the request of CACL, I was present throughout the trial. I lived in the area, was familiar with the case and, as a member of CACL's Advocacy Committee, had agreed to attend.

During one of the many recesses in the six-day trial, I was chatting to a well-known psychiatrist, an expert witness, there to give evidence of his professional opinion that Justin Clark was, indeed, mentally incompetent. As you probably know, Judge Matheson, rightly, found otherwise! The psychiatrist and I had met on occasions in the past, had even shared conference panels although I do not believe that we had ever spoken on the same side of an issue. As we chatted, he noted that Ian must be about the same age as Justin Clark. “I suppose you will be going through this process with Ian, soon, Audrey,” he said. My reply, I recall, was, “Over my dead body!” From that moment, I was hooked on finding alternatives to guardianship — amongst all the equally crucial matters in which I was already involved!

Article 19 recognizes:

“the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community...”

Today the world is a little bit safer

One thing I have noticed over my many years in the Association is that it takes little more than expressing an opinion to plunge one into responsibility for action! (Take heed! It happens! It works!) I was asked to chair a provincial Association Task Force on Alternatives to Guardianship which gave me the opportunity to express some of those long simmering notions. Some provinces were able to benefit from Ontario's ideas. Ontario, itself had only limited success. The subsequent opportunity to chair the CACL Task Force with similar purpose was seized with gratitude. CACL's team worked hard and from the efforts of that Task Force, the success of Inclusion International in getting Article 12 into the Convention evolved over time. Much effort and much heartbreak for both volunteers and staff has gone into that process. We have reason to be proud of the part we have all played in this international endeavour.

My only reflection, as a family member, is that we are not there, yet. We can never stop! If something is right, we have to work for it. It won't happen without us! Even supported decision making — such a simple and natural notion to many of us — looms before the legal world as a concept rife with pitfalls.

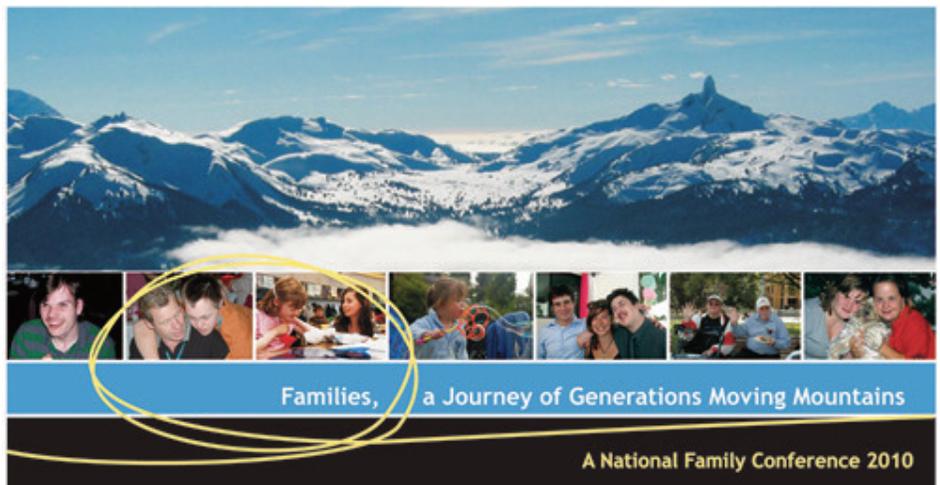
All Fred and I have to say, as rapidly aging parents, is that it is right! Hang in there and do it! We will be with you as long as we are able! Ian, although he may not know it, is depending on all of us!

Ray McIsaac

Port au Port East, NL

One of the many things the UN Convention helps to address for our family is “What happens after we're gone? Who will stand in our place, stand by, love and protect our family members like we do?” We are terrified that guardianship and not having full legal status could lead to events where a personal care home, nursing home or a group home might be in the future and this terrifies us. Someone else, someone who does not know or have the best interests of our son and daughter at heart could be in control of their lives and making decisions on their behalf. The Convention's declaration that all people have legal capacity and the right to act upon it, providing we

reform the laws in Canada to respect this new Convention, gives us much hope that we can make a plan to support our son and daughter, who have autism, to live in our family home. There are so many issues connected to this such as directing your own money, being able to hire your own staff, to have the right to support. Our son and daughter need assistance with many of these types of daily decisions but they certainly do not need a guardian to make the decisions for them! The UN Convention is one of the few (perhaps the only) rights based document that actually speaks to the issue of supported decision making as a necessary alternative to guardianship. Today we feel the world is a little bit safer for our family because of this remarkable breakthrough.



October 22-24, 2010
Fairmont Chateau Whistler
Whistler, B.C.
For more information, or to register
visit www.bcacl.org



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British Columbia
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Diversity includes.

When our words and our vision are heard

Susan Beayni
Toronto, ON

It is with great joy that Rebecca and the Beayni family heard that Canada was ratifying the UN Convention on the Rights of Persons with Disabilities. We were so proud of Rebecca when, in 2005 she made a presentation about her life and dreams to a group of people who were working on the draft of the Convention at the UN headquarters. She also made an intervention to the Caucus emphasizing the importance of family, friends and community in ensuring a good life for individuals. She stressed that interdependence needed to be the focus rather than independence and supported decision making needed to be included as a way for all people to have a say about what happens in their lives with the appropriate support provided to enable them to do this. We truly believe that Rebecca's presentation had an impact and that the wording of the Convention is, in no small way, due to the efforts of Rebecca and other persons with disabilities and their families.

The Secretary General said on May 15, 2007 in his message celebrating the International Day of Families:

"In its preamble, the Convention reconfirms that the family is the natural and fundamental group unit of society, and is entitled to protection by society and the State. It also states that persons with disabilities and their family members should receive protection and assistance so that families can contribute towards the full and equal enjoyment of the rights of persons with disabilities. On this International Day of Families, let us dedicate ourselves to enabling the family, the most basic unit of society, to fulfill its role in ensuring that persons with disabilities enjoy full human rights and dignity, and flourish as individuals."

We hear our words in this Convention; perhaps more than in any other Human Rights document. We see these words and this vision — our words and our vision — for families and individuals with disabilities gaining strength and power from being entrenched in



Simon, Nicole, Rebecca and Susan Beayni.

such an important document as a UN Convention. The task now before us, individually and collectively, is to use the convention to further embed and advance the rights of persons with disabilities and in so doing hold governments at all levels accountable for compliance with both the intent and spirit of the Convention.

The Beayni family is deeply grateful for the role that CACL, Inclusion International and the Canadian government played in developing the convention and advocating for its ratification. We look forward with hope and anticipation as the deep values embedded in this convention are set into action, enabling all individuals for whom this Convention was written, to live the full lives they want to live, participating and contributing as full citizens in Canada and the World.

In Memoriam – Cheryl Gulliver



Cheryl Gulliver passed away on Monday, April 5, 2010. Cheryl was an extraordinary voice of families and a stalwart

advocate for self-advocates at the centre of our movement. Cheryl was President of CACL from 1999-2003, and President of Community Living Ontario and Community Living Mississauga before that, an advocate in our movement for

almost 40 years. With her passing, Community Living has lost a good friend and passionate champion.

Cheryl had a passionate belief in families and the power and influence they could have. She spent countless hours reaching out, listening to and connecting with parents. As President of CACL, Cheryl was instrumental in creating a National Family Agenda. It was her number one priority. She was fearless in her advocacy, and traveled across the country

and around the world to bring a simple message to Prime Ministers, Premiers, Presidents, self-advocates, families, and community leaders — that people with intellectual disabilities and their families belong, like everyone else.

Cheryl will be missed by many — by her daughters Margot, for whom she advocated so relentlessly, Jennifer, and her beloved grandchildren and all the many friends she made throughout her life.

What *exactly* is a “convention”?

Gloria Mahussier
Prince Albert, SK

Canada ratified the UN Convention on the Rights of Persons with Disabilities on March 11, 2010. Hearing the news, sitting at my kitchen table I wondered, “What does that mean to our family? What *exactly* is a “convention”?

I know that Canada is a leader when it comes to promoting and protecting the rights of persons with disabilities and enabling their full participation in society. I knew that the signing was significant but I was not fully aware of the importance having our country’s

signature on a convention to our family. For clarity, I read the meaning of the word. I read that conventions can also be called “treaties”. It was clear — a “convention” is a legally binding agreement in writing. With the ratification, Canada has to follow the rules of the Convention.

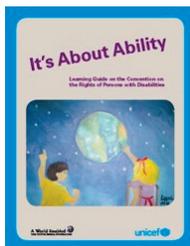
In Canada, each province has a Human Rights act, which defines a range of human rights, and everyone has entitlement to the provisions just because they are human. It does not matter whether you have a disability — you are human, the Act protects you. Signing the convention means, we now have an international human rights instrument to protect the

rights and dignity of persons with disabilities.

What does this mean to our family? For a younger Travis, our family could have used this as another tool to advocate against the discrimination towards our son because of his disability during his younger years.

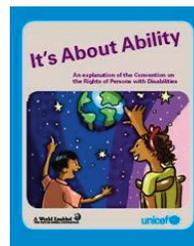
I think this is an opportunity for real system change. With this convention, each of us can affect positive change in Canada, albeit slowly. My dream is that we will accomplish this by changing existing legislation and policies to ensure provinces conform to the Convention’s provisions. “Go!”

Free Resources on the UN Convention for Children and Youth



It’s About Ability — Learning Guide on the Convention on the Rights of Persons with Disabilities

This learning guide is a companion resource to It’s About Ability: An explanation of the Convention on the Rights of Persons with Disabilities, developed by UNICEF and the Victor Pineda Foundation. Designed to empower children and young people aged 12–18 to speak out on the convention and become advocates for inclusion in their communities, the learning guide offers lesson plans and suggested activities to be used by young leaders, peer educators, teachers and other educators at the community level.
http://www.unicef.org/publications/index_50687.html



It’s About Ability — An explanation of the Convention on the Rights of Persons with Disabilities

This publication explains the Convention on the Rights of Persons with Disabilities to children. It’s main purpose is to empower children, with and without disabilities, to play their part in challenging discrimination and promoting the Convention’s principles.
http://www.unicef.org/publications/index_43893.html



Diversity includes.

CRPD: An agent for change or status quo?

(Continued)

and it provides people with disabilities and their families a new tool to promote and advance the rights of people with disabilities and to build an inclusive and accessible Canada.

Is it different enough to make a meaningful change in our lives? Can it be an agent of change? These questions are slightly more complex. Individuals and families aren't the only ones shaping the potential impact of the CRPD; international law doesn't have the same force as domestic law in Canada; accountability mechanisms are flawed. Do these shortcomings mean that we will see the continuation of the status quo instead of change? No.

The conditions for implementing and monitoring the CRPD may not be perfect but Canada's ratification turns a corner on disability rights. Broad sweeping change will not happen overnight but an empowered self-advocacy and family movement will not accept the status quo! Individuals and families are hungry for change and the CRPD provides them a framework to make it meaningful, practical and real.

There is much work to be done, beginning with Canada's ratification itself. Canada included a conditional reservation with its ratification stating that if the CRPD is interpreted to require prohibition of substitute decision-making arrangements, then Canada would reserve the right to continue to use substitute decision making arrangements where appropriate. CAACL and the Canadian disability community have expressed their concerns that the reservation is not in keeping with the spirit of the CRPD. Strategically we chose to celebrate ratification and work with the Government of Canada on developing and implementing supported decision-making legislation.

Canada has not signed the Optional Protocol that provides for a complaint mechanism at the international level. For the CRPD to be truly meaningful an implementation strategy must have a complaints mechanism. As a first priority we are calling on the Government of Canada to develop a cross-departmental committee with representation from community organizations tasked with developing an implementation plan.

The CRPD has great potential to be an agent of change and to make real and meaningful change in the lives of individuals and families. We all have a responsibility in making this happen. For individuals, families and disability organizations this means committing ourselves to learning about the CRPD; to using the CRPD as both an information tool and a legal tool; to believing that this time a human rights framework can be meaningful in our daily lives and that this time a human rights treaty informed by our voices, our experiences and our perspectives will make a difference.

Article 24 recognizes:

"the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive, education system at all levels, and life-long learning(...)"

Ten Objectives For the Next Ten Years

- Achieve equality rights and recognition.
- Close institutions and assure a home in the community.
- Secure child rights and needed supports.
- Ensure families have needed supports.
- Achieve inclusive education.
- Secure the right and access to disability supports.
- Establish safe and inclusive communities.
- Eradicate poverty for people with intellectual disabilities and their families.
- Achieve employment equality.
- Make a global impact on inclusion.

Our Ten-Year Agenda has ten objectives to guide how we'll realize our vision: communities, a country, and a world where diversity includes.

Join us in making this dream become true.
Visit www.cacl.ca



Diversity includes.

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Want more information on the UN Convention?

For the full text: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

For a powerpoint presentation on the Convention in Brief (scroll to bottom of page) <http://www.un.org/disabilities/>

For a plain language version: <http://www.inspireservices.org.uk/dwp.html>