

# coming together

...to create change

Winter 2009

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## Reflections on 2009

### National Action Committee on Family Leadership and Grassroots Engagement

As 2009 draws to a close we can look back, with pride, on the changes that have been created this year.

In the spring we all celebrated as Ontario closed the last of their large institutions. This brought to an end the era of segregating and isolating people behind closed doors. Communities in Ontario were instead opening up and welcoming all individuals.

On December 3rd, International Day of Persons with Disabilities, the Government of Canada announced its intention to proceed with ratification of the UN Convention on the Rights of Persons with Disabilities. Just one week later, on International Human Rights Day, the House of Commons unanimously voted to support ratification. It is expected that this ratification will happen early in 2010.

That same week two influential reports were released, suggesting that there will be movement by the Government of Canada in addressing the issue of poverty for people with disabilities.

There have been ongoing and positive changes within our federation, including approval (at the AGM in October) of individual membership in CACL for the first time in our history.

All of these changes, both internal and external, were years in the making, sometimes even decades. They happened because of the hard work and persistence of many people, people who despite obstacles and setbacks, always kept the vision of what we are trying to achieve foremost in their minds and who refused to give up. People like us – families!

Celebrate 2009 – reflect on and appreciate how far we have come this year. Then, as we embark on 2010, we must make sure our vision remains clear and strong and begin again to address the work that remains to be done.

Ontario might be institution free but other provinces are not. The UN Convention will be ratified but will it be implemented in a well planned and timely manner? Will Government act on its promise to address the unacceptable poverty level of persons with intellectual disabilities?

There is much work left to be done to create communities, a country and a world that accepts and values all individuals with intellectual disabilities and their families.

We must continue to come together in greater and greater numbers and make our voices heard. This year has proven that change is indeed possible! We must not lose the momentum!



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## 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

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## 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.



# Message from the President of NBACL

## Nancy Armstrong

President NBACL

Just over a year ago when I was asked to take on the role of New Brunswick's *Family Leader* as part of the National Network of Family Leaders, I jumped at the chance to meet families from across the country and share our journeys as parents of children with intellectual disabilities. The tapestries of our lives, experiences and environments have similarities and differences but we are inextricably woven together in our absolute determination to create more caring, inclusive communities.

More recently, I have been asked to co-chair the National Action Committee on Family Leadership and Grassroots Engagement. Over the summer months, this group has developed a work plan that will hopefully keep us constantly renewing ourselves and our family leadership from coast to coast. Engaging families is an issue we as a Federation struggle with, whether we are urban or rural, large or small organizations.

At home in New Brunswick, NBACL began the formal process of a Grassroots Engagement Initiative over two years ago. In order to better engage families and allies, we first needed to know how we were doing as an organization. And

so, however humbling, we approached families, local associations, and community partners and asked those tough questions: What are we doing right? What can we do better?

This process now permeates all aspects of our work. Supporting families, family networks, and family leadership is integrated into every aspect of our Strategic Plan. We hired our first Family Support Coordinator, and aim to have one in each of our seven geographic regions. It will take many more small steps, but I am excited as families take up again their position as the driving force of the organization.

The National Action Committee on Family Leadership and Grassroots Engagement is timely for New Brunswick, but I am certain it is timely for all of us across the Federation. I am encouraged by the national focus on family leadership.

Now it is my pleasure as a very new President of NBACL to get to work even more closely with those high achieving, won't take no for an answer, will settle for nothing less than full equality NBACL volunteers and staffers who have set the social policy bar so high in this province because nothing else will do.

# Building a Social Movement for Inclusion

## Michael Bach

Executive Vice-President of CACL

**W**hen the National Action Committee on Family Leadership and Grassroots Engagement, and the National Network of Family Leaders appointed by Provincial/Territorial Associations for Community Living (PT ACLs) met at our national conference in Moncton in October, we considered what I think is a burning question for us all as we approach 2010: How do we become more effective in pursuing and achieving our 10-year Agenda? In this article, I share some of my reflections on our discussion.

***Why isn't our federation effective enough yet to successfully pursue and achieve our 10-year Agenda?*** I think the primary reason is that our aim is now different than it was in the 1950s and 1960s. Then it was primarily to build a service system to support children and adults with intellectual disabilities – and ACL leadership was extremely successful in securing resources to do so. However, by the time we got into the mid 1970s and in particular into the late 1980s and 1990s our vision began to expand as the human rights revolution began to take hold in our associations and movement.

Where are we now? We are inspired to make change possible for all, and to realize the promise of human rights. But we have a way

of organizing that that is still largely rooted in the service thinking and mission of the 1950s and 60s. We are a federation of over 400 local along with provincial/territorial ACLs. At the local level, we have a variety of associations – sometimes small or large ACLs – focused primarily on delivering an array of supports and services. In some communities, we are remarkably vibrant local associations which, along with the support of PT ACLs, are showing how communities can be transformed. In other communities our locals are struggling to survive, or have closed their doors, and in many more ACLs are simply nonexistent.

We are realizing that to be more effective we need to become much more of a social movement than only a federation of organizations – a social movement of family and allied leaders, a grassroots movement engaging self-advocates, families and community members linked through networks of people and organizations and in common cause.

***Why organize as a social movement?*** Because we want power and influence, not as an end in itself but to bring about change. We want power to change minds and change communities. We want power to change how teachers think and how schools work; how employers hire, and run their workplaces. We want power to get our voices and stories and perspectives into the media –

newspapers, radio and TV. But the reality is we do not yet have the power we need to achieve the vision and mission we have set for ourselves.

A social movement is a means to mobilize this kind of power. It is based on the idea that if we work collectively, rather than leave people isolated and alone in their lives, we can tap energy and mobilize commitment to bring about transformational and systemic change. If we now want that kind of change, we need to organize as a social movement.

So how do social movements mobilize power to change hearts, minds, communities, public policies? Networks are the new political actors with the power to shape political agendas and bring about change. Global financiers and media leaders recognize that today power – for better or worse – is mobilized through networks, and so do effective social change movements.

***What kind of networked social movement do we need to pursue and achieve our Agenda?*** One that makes collective action possible at all those places where we know change is needed – in the minds and values of Canadians, in hopes and expectations and energy of families; in schools, workplaces, child care centres, in governments, in the media. We need a networked social movement that engages in town hall meetings, political

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# A Parent's Perspective on Poverty and Intellectual Disability

**Leila Rahemtulla**



I recently had the honour of participating in a national Poverty Forum in Vancouver, BC. Based on the statistics presented at the conference, a person with an intellectual disability is almost three times more likely to live below the poverty line when compared to the general population. The issue of poverty is also a family affair and I wanted to share some insights from that perspective.

The first important point parents make clear is that “our children are our gifts, not our burdens.” Speaking for my own family and many others, it is important to remember that although our challenges may be great, we love our children unconditionally. Our children are not our burdens, what is missing in their support is the burden. For many, caring for their adult child is not a choice—it is the only option they can fathom. We must ask ourselves if it is right that the social net has shrunk because of the assumption families will shoulder the care of their child indefinitely. For some, there is a feeling that loving their children has sometimes been used against them—almost like emotional blackmail—when families ask for help, their unwillingness or

inability to carry on is equated to not caring.

Having a family member with an intellectual disability usually means there are costs as well to the family—to careers, home, the other family members and life overall. For instance, we as a family moved back to Canada when our son was born so we could offer him a better life. What happens when you don't have the finances to move, the education or work that gives you freedom, what if poverty is already your family's reality? Families “do the math” and resign themselves to the fact that if they don't keep care in place, chances are their child will live in poverty. This is the reality for many families—they really don't feel there are other options.

I know a single mom caring for her adult child while fighting cancer; she has had to try to work to keep her son's life managed and it left her little time and energy for her own healing. For another family, the cost was a couple's relationship. Other families choose lower paying jobs or no job at all if there is not enough flexibility to care for their child. There is a cost to siblings and extended families—these are the people that may not get the care or attention they need or make their own sacrifices as families try desperately to make it work. These are some of the real costs that need to be included with the financial data—the costs to relationships, wellbeing, family life, and careers.

There is a vulnerability that is created when you ask a family to talk about poverty. Sometimes families feel exposed or

embarrassed or guilty as a result of conversations they have had to have with support or financial workers. We can never lose sight of how deeply personal this issue is for families. We must be careful not to strip away someone's power—in fact, I believe our focus needs to help restore it. None of the families, including my own, want pity. That destroys our power. What families want is understanding, what they need are supports for their family members, what they live for is to provide their family members a good life—one filled with love, dignity and fulfillment. This requires listening without judgment and honouring the family and its dignity.

During the panel and the conference I was reminded that within each family lives a story, a lifetime of joy and challenges and ultimately a need to want to make it work. Families want to engage in a dialogue that honours families in their choices, respects them in their financial condition and treats them as individual, unique units that we all have to take the time to get to know and understand. This work gives me faith—that we live in a society that dares to care, that has the courage to stand up for fundamental human rights for all people and breaks down the differences between us. When we get to that, we start to care about each other in a way that can truly transform society—and that is the one thing that gives me hope as I raise my children.

*Leila Rahemtulla is a member of the board of BCACL. She and her husband live in Vancouver where they are raising their two sons.*

# Maritime Family Kitchen Party — a true success!



The weekend of October 23-24th was one to remember at the Ramada Plaza Crystal Palace in Dieppe, New Brunswick, thanks to the hundreds of families, self-advocates and friends from across the country who came together to share and learn at the 2009 National Family Conference, co-hosted by NBACL and CACL. The conference programme was full with workshops, guest panels, speeches, dinner, dancing, and amusement park rides, and all participants left in full agreement: there was something for everyone!

Eager participants got a jumpstart Friday morning with a pre-conference workshop hosted by Jack Pearpoint, who spoke on organizational practices and capacities that improve person-centered work.

The conference officially opened on Friday evening with speeches from several distinguished guests including Conservative Leader David Alward, former NB Premier

Bernard Lord, and the honorary president of NBACL, former Fredericton MP Andy Scott. Though from different political backgrounds, all three agreed and spoke on the importance of community living values and the principles that must be upheld and fought for in order to become a truly inclusive society.

Former Premier Lord pointed out that community living principles and ideals are not only important, but are also a defining characteristic here in Canada. Andy Scott reinforced that point, saying, “We always hear people say that Canada is a tolerant society, meaning we tolerate difference. We don’t just tolerate difference. We celebrate it. We love it. And we may be the only country that really gets it.”

The conference continued Saturday with an early morning media panel, and sessions on topics ranging

from education and early learning, aging parents, transition and future planning, and even effective uses of online social networking. Saturday evening’s closing dinner featured Social Development Minister Kelly Lamrock speaking on the importance of diversity and inclusion in all aspects of our community. For those conference participants who weren’t too stuffed full of the traditional East Coast fare, La Famille Arseneault wrapped up the night by providing plenty of opportunity to play the spoons, tap your toes, and brush up on your French!

Being a true family conference, we did not forget about the children. While parents were enjoying the conference sessions, the children were also having lots of fun. Childcare opportunities included trips to the indoor theme park and an offsite Sibshop, which provided an opportunity for young children to get together, have fun, and share some of their thoughts and experiences on having a sibling with an intellectual disability.

NBACL and CACL would like to thank their staff and the Conference Committees for their hard work over the past year. NBACL would also like to thank their generous conference donors, who sponsored over 50 NB families and self-advocates to attend the conference. Most of all, thank you to the families, self-advocates and friends who joined us this past October and made the 2009 National Family Conference a true success! See you in Whistler, 2010!



Diversity includes.

# Around the Country

## Saskatchewan

In 2004 the Saskatchewan Association for Community Living launched an innovative new program – Adopt-an-MLA. Provincial politicians routinely make decisions that can have a major impact on the lives of individuals with disabilities and their families, yet many had no knowledge of the issues or the impact of those decisions. The goal was to connect every MLA with a family in their riding. The MLA would come to the family home for a cup of coffee and a visit. This gave them an opportunity to meet all members of the family and to listen to their stories and concerns. This program has been a huge success and has certainly raised awareness of our issues within government. It gave families the opportunity to have their voices heard and in fact, as families were empowered through this process, many are now more comfortable contacting their MLAs as issues arise.

On November 4/09, we took this one step further. The SACL Family Network hosted an evening event in Regina and invited all MLAs to attend. We wanted the MLAs to spend time with families in a fun, social context – to see first hand families celebrating together and experiencing the joys their children bring to their lives. The turnout of MLAs was very good. Everyone enjoyed the entertainment provided by SACL's Kids on the Block puppeteers and had pizza and cake. The response from both families and the politicians was very positive!

One of the MLAs present that evening, Cam Broten, spoke in the legislature the next day and made the following comments – “It’s an



*Cam Broten MLA in discussion with Olivia Dueck*

opportunity to get to know one another on an informal basis, a basis of friendship. Mr. Speaker, probably the best way to get to know someone better is to share a meal together. I know I thoroughly enjoyed the conversation at my table as we filled up on pizza and chatted about life. Over the course of the evening, I heard about the issues that matter to families – whether that was about

transportation needs, community supports, or recommendations on how things could be improved.”

In Saskatchewan, SACL and it's Family Network will continue to look for opportunities to reinforce that connection with our elected officials and to ensure that the voices of individuals with intellectual disabilities and families continue to be heard.

## Yellowknife Association for Community Living's Family Networking Group — A Parents Perspective

Submitted by Shauna Henry,  
NWT National Network of Family Leaders Member

Five years ago our little boy Jack was born. A little angel, he had dark hair, lovely eyes, a perfect nose and beautiful lips. Our first-born, what a beautiful day it was! Jack happens to have Down Syndrome and as parents we had no idea how enriched our lives would be from that day on.

Some feelings that come to mind as new parents of a child with an

intellectual disability are: fear, anxiety, overwhelmed and the list goes on. Being from a smaller city in the north, we wondered how on earth we would ever be able to do this. How do we do what is best for our new bundle of joy? Who is going to help us?

This is where Yellowknife Association for Community Living came in — an amazing organization

# Upcoming Events

that sat with our family and steered us in the right direction. One of the initiatives that we learned about and has been invaluable to us, is the Family Networking group. It's a group of parents and caregivers that meet once a month. The evening consists of some networking time in the beginning, usually a guest speaker sharing information specifically tailored to our needs, and then more time for networking. The Association also provides respite workers on site to take care of all of our children while the meeting is ongoing. Oh yes, and always plenty of coffee, tea and treats!!!

What is really neat about this group is how diverse it is. There are those of us who are fairly new parents and then there are individuals who have been supporting a family member with a disability for 20-30 years. It is amazing the amount of knowledge, experience and compassion that actually sits in that room where we meet. Very encouraging! Not only does it give families an opportunity to meet others and increase their social networks, but it also gives families time to share, and by sharing we mean the good, the bad and in between. We as families, for a change, get to be the "norm". Nobody stares at our family member or us; we are all the same at these meetings, and it definitely reduces any feelings of isolation we all might have. My husband, our three children and I look forward to a night out every month with this Family Networking Group and would certainly feel lost without it. I cannot put into words our appreciation to this Association for all its support.

## Northwest Territories

### Transitions Service Fair – High School to Community

The purpose of this event is to help families understand the importance of planning for their child's school to community transition and learn about resources available to their child upon finishing school.

When: Wednesday, March 24, 2010 from 6-8 pm

Where: École Sir John Franklin School

For more information contact: Yellowknife Association for Community Living

Phone: (867) 766-4294

E-mail: inclusion@ykacl.ca

## Newfoundland and Labrador

### Summer Institute

#### Inclusive Education Practice: Effective Leadership for Schools and Communities

When: Sunday, August 1 – Tuesday, August 3, 2010

Where: Memorial University of Newfoundland, St. John's NL

For more information contact: Donna Walbourne, Community Inclusion Consultant, Newfoundland & Labrador Association for Community Living

Phone: (709) 722-0790

E-mail: donnawalbourne@nf.aibn.com



Newfoundland & Labrador  
Association for  
Community Living

## British Columbia

### 2010 National Family Conference

SAVE THE DATE!

CACL, BCACL and Family Focus are pleased to host the 2010 national family conference.

When: October 22 – 24, 2010

Where: Whistler, BC

More details to follow in the Spring edition of this newsletter.



Canadian  
Association for  
Community Living

Diversity includes.



British Columbia  
Association for  
Community Living



Diversity includes.

*What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal.*

— Albert Pike

## Building a Social Movement for Inclusion (Continued)

conventions, and online forums where public dialogue now takes place.

What kind of collective action are we talking about that ‘switches on’ our Agenda to others with power to make change happen – allied professionals, media, politicians, employers, service providers? Action can take many forms – from people forming peer support groups and ‘networking’ by talking and listening to each other, by creating online communities and learning/knowledge networks, to organizing partnerships and collective engagement with the child care or education system, to cultural production. It can be mass letter-writing campaigns, it can be protests, it can be coalitions (like End Exclusion), it can be public awareness campaigns. We need multiple forms of action – and local to global networks can make it happen.

***Are we positioned to support and help sustain a growing family-led social justice movement?*** There are growing family networks, but they are largely disconnected from one another if we take a national view. There are vast numbers of self-advocates and families who are not connected, don’t know about us, and many young families don’t want to join the local base of our organization – that’s not universally the case, but I think we all recognize it is a major issue. There are many communities where local ACLs are not positioned or mandated or have the capacity to support the broader family movement.

I think it is time that as a national federation we look collectively at the capacity of our local infrastructure and ACLs and ask if we are tooled up and organized to support a growing family movement – with information about what families want, support to help organize, and technologies and human resources to assist families link up and mobilize for change. This is about deciding who we are as a national federation in 2010, what our Agenda is, and how we organize ourselves to support a social movement that can achieve that agenda. Over fifty years ago, families knew the answer lay in the power of networking. Let’s return to those roots, and mobilize the power of those ideas to respond to the vision and challenges of today.

## 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](http://www.cacl.ca)



**Diversity includes.**

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