

# coming together

...to create change

Summer 2010

A National Family Leadership newsletter



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## The World Comes Together to Create Change!

Inclusion International held their 15th World Congress in Berlin, Germany from June 16th to 19th and the world showed up! This was the largest event in the history of Inclusion International with over 2700 people in attendance. People with intellectual disabilities, family members, policy makers and professionals from more than 80 countries were involved in the four day event. The theme of this year’s Congress was “Transforming Global Rights into Action” and the focus was on the UN Convention on the Rights of Persons with Disabilities.

Canada was well represented at the Congress with representatives from CACL, People First of Canada, ACL Manitoba, SACL’s Self-Advocate Action Group (SAAG) and other individuals participating. Representatives of CACL and PFC presented in a number of sessions and the SAAG group did a presentation at the Speakers Corner.

Of special interest to families were the sessions on “Empowering families and all their members” and “How families can use the UN Convention to promote change”. Laurie Larson, VP of CACL, presented during the empowering families session and spoke about the work that we are doing in the area of family leadership and grassroots engagement in Canada. This work resonated with those from other countries as they too look to strengthen

the capacity of families to create change. Larson commented that, “When we all get together at events like this, connect and share stories, what becomes clear is that families are families no matter where they live. We have the same experiences, the same hopes and dreams, the same challenges and concerns.” Family members expressed an interest in finding ways to stay connected after the Congress was over.

The World Congress also marked the end of Diane Richler’s eight years as President of Inclusion International. It was very clear just how much the international community valued the leadership that Diane has provided and all that she has accomplished during her term. Canada can be very proud of the example that Diane has set for the world.

The World Congress was a very rewarding and inspiring experience for those who were fortunate to attend. Melody, a SAAG member from SK, said , “This was a life-changing experience for me...” and Lynne Harley, SAAG Co-ordinator commented “Watch out Saskatchewan... it will be hard for these self-advocates not to think BIG upon our return to Canada and after all that they have experienced”. With over 2700 people leaving the Congress in Berlin inspired and ready to create change it may be safe to say “Watch out world!”



## Message from the President of the Saskatchewan Association for Community Living

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

Laurie Larson – Chair, CACL  
Julie Smith – PEI  
Kevin McTavish – SK  
Kim Aker – NS  
Dawn Gates – MB  
Leila Rahemtulla – BC  
Shauna Henry – NWT  
Tara Brinston – Secretariat, NBACL  
Anna MacQuarrie – support, CACL

### 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.

### Photo Credits

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### Gloria Mahussier

President  
Saskatchewan Association for Community Living

Prince Albert, March 1997 the SACL Family Conference session, *Family Networking – Living the Vision*. I was there. I did not realize it at the time, but that experience would affect my life's journey for the next thirteen years. The presenters spoke about the passion, the pain and the power of family networking.

The SK Family network began with 17 families in 1998. In late 1999, I along with some families were brought together for a SK Family Network event. I took pictures of our group, and I thought: Life will never be the same for me again. As we connected, I found I had lots in common with these families. I knew I was not alone and through the years I discovered that families with a sense of common purpose, called upon to act together, can make a difference. The network was 70 families strong in 35 different communities and through 1999 families took advantage of five regional gatherings to connect. Our 2010 annual report of the SK Family Network reported 426 families and 13 family events.

Every member that passes through the Family Network has their causes, their concerns and their issues worth fighting. To share a sense of purpose and a set of values with those around us is a part of what it means to belong to a just and civil society.

The SACL passed a resolution placing renewal as a grassroots movement as a priority and with this to adopt a process of renewal as a family movement. This is a priority for the upcoming year, as we work towards our mission, "to ensure that citizens of Saskatchewan who have intellectual disabilities are valued, supported and included members of society and have opportunities and choices in all aspects of life."

Looking ahead, I know the year will not be one without its challenges and the SACL Board of Directors look forward to supporting the initiatives. We are an organization willing to challenge what currently exists and will provide the strong support on the issues for families. SACL is also pleased to be able to contribute to the work being done nationally on family leadership and grassroots engagement by participating on the National Action Committee.

To quote a friend, "Families must be involved in disability issues if we are going to get people the right support in the right places." Our primary focus of family engagement will become stronger as we find our next leaders.

### Study Paper on Family Caregiving

*The British Columbia Law Institute and the Canadian Centre for Elder Law have now released their study paper, **Care/Work: Law Reform to Support Family Caregivers to Balance Paid Work and Unpaid Caregiving**. "Family caregivers face significant work-related consequences such as short-term and long-term poverty caused by a loss of employment income," said Staff Lawyer Krista James. "Court decisions suggest a trend of not supporting workers who require workplace accommodation in order to balance work and care. Family caregiving saves the health care system a lot of money. It is time to question whether the law should provide caregivers with more job protection and greater benefits."*

*To download a copy of this report go to this link:*

<http://www.bcli.org/ccel/publications/study-paper-family-caregiving>

# Alberta Association for Community Living Family Leadership Series: 10 years

## Anne Hughson

Director, Community Rehabilitation & Disability Studies, Faculty of Medicine, University of Calgary

## Bruce Uditsky

Chief Executive Officer, AACL

Ten years ago the Alberta Association for Community Living launched its first Family Leadership Series. To-date more than 300 family members, primarily parents, but as well adults with developmental disabilities including some who were parents themselves, siblings, grandparents and even godparents, have participated in the 5 weekends of intense learning that constitute the Series on an annual basis. The Series was developed by Anne Hughson and Bruce Uditsky. The Series would not be possible without the highly skilled leaders who volunteer their time, often year after year, to facilitate the small group processes that are integral to the Leadership Series.

The decision to formally and systematically engage in family leadership was based on the understanding that an investment in family leadership provided the greatest dividend for a more promising future for children and adults with developmental disabilities. From its inception this Leadership Series was predicated on the value of multi-generational collective leadership and the need to foster and deepen AACL's capacity for advocacy and social change. In order to thrive and advance a vision of inclusion over time, advocacy organizations need to be in a constant process of renewal and reflection. The Leadership Series has been a significant and sustaining force for



renewal as family members from across generations and cultures enhance their shared vision of inclusion and the actions required to create more inclusive communities. Given the challenges faced in the course of a lifetime commitment to inclusion, there is an inherent necessity for hope to be sustained and renewed within families. The Leadership Series has proven to be a continuing and vital means of renewed hope.

During the 5 weekends participants explore the following topics, and others, through a process of presentations, small and large groups discussions, guest speakers and case studies: values-based leadership; the history of the community living movement; systemic and societal devaluation; normative pathways; inclusion across the life-span; strategic networks; systems and personal advocacy; critical analysis; community capacity; inclusive education; personal inventory of strengths and limitations; policy and legislative analysis and action implementation. Addressing these sometimes challenging topics requires both the creation of a safe place and all the time necessary for

sufficient discussion. The Series does not use a standardized or typical curricular approach that attempts to teach assumed leadership skills. The approach of this series is grounded in the concept that there is wisdom within the group of participants and by using an interactive process this wisdom can be drawn out and applied.

At the conclusion of each series, many of the participants are interviewed and asked to comment on their experience. Some of the experiential commonalities that have emerged over time include the following: clearer vision of an inclusive life and the means to that end; deepened and shared values; a commitment to speak out on issues; better appreciation for strategic thinking and action; a deeper understanding of the struggle to be included and valued; better understanding of personal strengths and weaknesses; increased capacity to act individually and collectively. To help continue the learning AACL holds a leadership reunion every year for past leadership participants. This provides AACL with the opportunity to have its

*Continued on back page*



Diversity includes.

# Long Time Advocate Provides Inspiration to Families

**Darcy Cameron**  
NBACL

On Wednesday, June 30th, Her Excellency the Right Honourable Michaëlle Jean, Governor General of Canada, announced the appointment of Dr. Gordon Porter as a member of the



Order of Canada. Dr. Porter is the former chair of the New Brunswick Human Rights Commission and Director of Inclusive

Education Initiatives with the Canadian Association for Community Living. He is also a past President of CAACL.

A native of Woodstock, New Brunswick, Dr. Porter has been a leader in promoting the rights of children who have disabilities, and a lifelong advocate for inclusive education practices – a subject he has consulted and taught on in over a dozen countries throughout the world. His dedication to this work has been inspiring, influential, and important to the lives of many individuals who have an intellectual disability and their families.

One such family is that of Marlene Munn, whose daughter Aimee has Down syndrome. Inclusive Education is a subject that has always been close to their hearts as they have helped their daughter navigate her way through the public school system. Being from a small town and not having much experience with Down syndrome, the family became connected to

The New Brunswick Association For Community Living in search of information and resources. It was there that they had their first contact with Dr. Porter.

“I was always concerned about Aimee’s education and whether or not she would be welcomed and included,” says Marlene. “Gordon Porter always said that inclusive education is more about a way of thinking than a question of resources. With that in mind, the possibilities for Aimee’s future seemed to open up.”

Aimee is now 11 years old and her educational experiences have been immensely positive, both for her and for her classmates. When we are all included and treated as equals, everybody benefits.

Although Marlene is grateful for the opportunities and benefits her daughter has been fortunate enough to receive, the positive experiences she has had, and the friends she has made by being included in classrooms with her peers, she is also aware that there are a lot of other kids out there who haven’t been given the same opportunities and wonders why so many others continue to be left out.

“We still have a lot of work to do,” she says, but adds that it is precisely this continuing work that makes the people who work on behalf of children like Aimee so inspiring. “The reason I’ve found people like Gordon Porter, the staff at NBACL, and others like them so inspiring is that they do this work because they truly believe in it, they believe it is the right thing to do, and they believe this kind of work will make the world a better place for everybody.”



Witnessing this kind of work first hand and seeing the difference one person can make in peoples’ lives also inspired Marlene to become more actively involved. She is currently the President of the New Brunswick Association For Community Living, and through her involvement she has been able to get a better view of the hard work people like Dr. Porter dedicate themselves to everyday and the impact it has on communities and families.

Seeing Dr. Porter named to the Order of Canada is an honor that Marlene believes is important and well deserving.

“NBACL is very proud of the achievements of Dr. Porter, who has dedicated his life to ensuring that all children here in New Brunswick, as well as nationally and internationally have the necessary supports to learn, participate and contribute fully in every aspect of school life,” she says. “He deserves this honour not just from the intellectual disability perspective, but also from the human rights perspective.”

Dr. Porter’s work has been facilitated and recognized all over the world. “He has done a lot for individuals, for families, and for children with an intellectual disability who deserve to be included in their classrooms and participate just like everybody else,” says Marlene. “It’s great to see him get the recognition he deserves.”

# Evolution of a Grassroots Leader

## Sarah Hauptkorn

Community Living - Manitoba

When Irene Maendel talks about the importance of meaningful relationships for all, she comes alive. Irene says that after receiving news of her son Jamie's diagnosis, she "was consumed with helping him be the best that he could be." Passionate about working with people to create change, Irene demonstrates the power of positivity, advocacy and grassroots leadership.

Irene was born and raised in a Hutterite colony. In 2005, with husband James and their two children, she "took a leap of faith and left that sanctuary—a decision that required a lot of prayer and whole lot of planning." Leaving this security and comfort behind was daunting; however, it was time to explore new possibilities.

Irene negotiated with Hanover school division to enrol Jamie in the transition program at the Steinbach Regional Secondary School. There he really benefitted from interactions with peers and young educational assistants. Irene was delighted one day when Jamie told her, "Mom, wait—I'm thinking in my brain". This was confirmation that public school was the best choice for Jamie.

She began working for enVision Community Living, and "was amazed that families were having their children with disabilities move into homes of their own to be supported by paid staff." During that time she began courses in disability studies.



Jamie and friends, shooting hoops and just having fun.

"As my knowledge grew in the field, the way I supported Jamie at home started to change, and he began to flourish and become more independent."

It was an eye-opener for Irene to see how various organizations offer supported living options. She had never considered anything like this, being so entrenched in her thinking about families caring for their own. "The first half of the year I had many discussions with my advisors, thinking that their views of inclusion and young people gaining independence were unrealistic. It's very hard for families to care for their own alone—I began to see this. Families are likely to just give up." Irene's perspective was evolving.

"What I do now is a perfect fit; creating support networks around people and helping them find meaningful relationships. Basic support is important, but the most significant part of anyone's life is healthy relationships."

Irene noticed that although many supported living options exist in Winnipeg, this is not the case in rural areas. She began to network and talk to families in the region, coming into contact with more people who wanted to be part of

new, creative options in supporting people with disabilities and their families. PartnersaNew, a supported living organization offering "flexible, person-centered supports" in south-eastern Manitoba, was born.

"My son will soon be graduating from high school, and will lose the benefits of the relationships and connections he now has. I want him to have the option of taking his time, living with our family as long as he needs and wants to." Through her work with Community Living MB she realized that other families are expressing similar wishes. Her vision includes integrated, community-based, innovative supports based on personal relationships and strong in family connections. Irene's personal experiences with Jamie have taught her the value of quality supports and access to information.

Irene Maendel will continue to advocate for, promote and foster inclusive, healthy communities rich in values and relationships. By building on personal experiences and connections with friends, families and acquaintances Irene has become a leader and a role model in her community.



Diversity includes.

# Federal Policy Forum on Inclusion

**O**n June 4th, the first annual Federal Policy Forum on Inclusion was held in Ottawa. The forum was co-hosted by the Canadian Association for Community Living (CACL) and People First of Canada (PFC).

The purpose of the Forum was to 1) build awareness among families and self-advocates about the federal policy environment and 2) engage in dialogue with the federal government about our Agenda and ways it can be advanced. This first Policy Forum on Inclusion focused on the broad issue of Poverty with specific discussions held with respect to four theme areas: Income, Employment, Housing and Legal Capacity.

The forum represented one of the first real formal opportunities that we, as families, have had to both listen to and engage in conversation with policy makers at the federal level. The forum allowed an opportunity for us to hear first hand as to intention and policy direction of the federal government as related to these issues and more importantly provided an opportunity for us to



share, directly, with federal officials our position with respect to these important issues.

At the Forum, the official policy position of CACL and People First of Canada was presented as related to each of the four issues, and more importantly panel presentations were given by family members and self-advocates on the real life impacts and implications of inadequate policy development and delivery in each of these areas. The presentations by families and self-advocates were extremely powerful and provided the federal officials in attendance with the lived experience of how policy really does impact on families and individuals. These personal stories gave urgency to the need for immediate improvements in these areas.

While it would be naïve to expect

that as the result of this one day forum we will witness substantive changes to the federal policy context, it is nonetheless important that we as families engage with our federal government in these types of conversations and debates. It is important that policy makers understand that policy should not dictate how we live our lives but rather that how we wish to live our lives should dictate policy. We know that creating the kind of positive social change we want in this country will not happen without such dialogue and without a fundamental understanding and acknowledgement of the important role that must be played by families.

The various Policy Position papers and Fact Sheets on each of these areas are available on the CACL website. [http://cacl.ca/english/priorities/position\\_statements.asp](http://cacl.ca/english/priorities/position_statements.asp)



## *In Memoriam* – Karen Gledhill

On June 14th, our Federation lost a passionate and dedicated leader, advocate, and a dear friend when Karen Gledhill passed away after a long and courageous battle with breast cancer.

Karen had been the President of Community Living Ontario, a member of the Board of Directors of CACL, and an active participant on numerous national committees. To each role Karen brought grace, charm and integrity, combined with a keen appreciation and understanding of how our movement fits within the larger human rights and social justice framework. She was a tireless worker as confirmed by her longstanding and ongoing contributions to the community living movement at the local, provincial and national levels.

As a member of our movement, and more importantly as a parent of a child with an intellectual disability, Karen was acutely aware of the important role and associated contributions that are made everyday by parents. She was ever vigilant in ensuring that a parent perspective was always fully considered as we worked toward the attainment of our vision and goals. She was a major proponent of our efforts to reengage with families and our grassroots.

Karen's commitment, dedication and passion will be sorely missed within our Federation.

# Focus on Family Engagement and Leadership in British Columbia

**Karen De Long**  
BCACL

Through a variety of actions and activities, BCACL is committed to bringing families together. We believe that families are the very foundation of our work and we need to look to them for leadership and direction.

The "Pathways to Citizenship" project, funded by the federal Office of Disability Supports, allows staff and volunteers to travel to communities across BC for a weekend retreat full of sharing and listening. Each year, a different community is chosen and families from the surrounding area are invited to attend a 3-day event aimed at reaching out to and strengthening families with young children. Often the most powerful

part of the weekend is the panel of parents. Their stories of institutionalization and total segregation are not experienced by young families today and many retreat attendees are moved and shocked as they listen to the personal stories from this era. This is always an emotional section of the event and is often the catalyst for new family connections. In an effort to cement our relationships with these communities BCACL staff returns to each community a year later for a day of reconnecting.

A unique partnership between three separate family organizations has been created in preparation for a national conference entitled "Families, a Journey of Generations Moving Mountains" to be held in Whistler, BC October 22-24th. The Family Focus Society, the Canadian

Association for Community Living and the BC Association for Community Living have joined forces to plan and present this conference together.

The Family Focus Society has been organizing conferences for families, by families for more than 20 years. Many of the family members who attended past conferences have become active leaders in their community and at the provincial advocacy level. BCACL is excited to be co-hosts with the Family Focus board of directors and representatives from CACL. The collective expertise from each organization will provide a well-rounded approach to providing a conference for families which will include child, youth and adult-focused programming as well as workshops for those who provide support.

## Register now and save!

Registration is now open for the 2010 National Family Conference, *Families, a Journey of Generations Moving Mountains*.

The conference will be held from October 22-24, 2010, at the Fairmont Chateau Whistler.

From now until September 10, 2010, you can take advantage of the special conference rate. Register online now at [www.familyfocusconference.com](http://www.familyfocusconference.com) and choose from over 50 informative, interactive, fun sessions, great networking events and hear from the most innovative thought leaders in community living.



Are you a person with a disability or a family member who supports a child or adult who has a disability? Check out our special \$150 Family Member/ Self Advocate Fee. For this special rate you can get two days of sessions that will give you the tools you need to move mountains!



Diversity includes.



Members of SACL's Self-Advocacy Action Group and their supporters attended the 15th World Congress of Inclusion International in Berlin, Germany.

## Family Leadership

(Continued)

grassroots leadership from across the province contribute to the organization's direction.

As a result of the Family Leadership Series, AACL is now a more effective family advocacy organization. We have had the pleasure of parents from other countries spend time with us to learn about the Leadership Series and other AACL activities. In turn family leaders from AACL are now being invited to other countries to share their learning and experience. The pool of leadership talent available to AACL now and into the future continues to grow, demonstrating the benefits of an organizational commitment to grassroots leadership development.

## Western Canadian Conference on Leadership for Inclusive Education: Raising the Bar and Getting Results

Sponsored by



University  
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University of Regina  
Regina, Saskatchewan  
November 4-6, 2010

Details to follow—keep informed with updates at [www.inclusiveeducation.ca](http://www.inclusiveeducation.ca)

For information—email us at [inclusiveeducation@cacl.ca](mailto:inclusiveeducation@cacl.ca)

## 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)



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