

# coming together ...to create change

## A National Family Leadership Newsletter

Volume 9, Issue 1 - Spring 2016



### inside

**We are rocks because we are not islands** 2  
*Angela Loepky*

**You think you're the only one** 4  
*Christy MacLean*

**It takes a community** 6  
*Nicole Martin*

**Inspired by a child** 7  
*Patricia Franks*

**How making real connections can change everything** 8  
*Laurie Frandsen*

**A National Family Leadership Series** 10

*Coming Together... to Create Change* is compiled and produced by the CACL Family Voices and Agenda Task Force to highlight the power of families to affect change and advance Inclusion.

## The importance of connecting

Message from Dianne Cormier Northrup  
Chair

CACL Family Voices and Agenda Task Force

My name is Dianne Cormier Northrup. I'm a mom of two adult children (48 and 45), Board President of the New Brunswick Association for Community Living and the newly appointed Chair of the CACL Family Voices and Agenda Task Force. Throughout the lives of my children, connecting with other families has been an important part of helping me feel supported and better equipped to deal with the challenges of parenting children with significant disabilities.

Families, no matter where they are and what form they take, rely on other families and the support of their communities to face the responsibilities and challenges of raising children as well as to celebrate joys and successes. In addition to the formal supports like school, health and social services, recreation programs, etc. families also rely on informal supports from extended family, friends, and people they meet in their neighborhoods or at the library, park, pool, etc...

In addition, many parents of children with a disability discover at some point how important it is to connect with other parents who share similar life experiences and

challenges they are facing and who know firsthand the feelings they are experiencing. Connecting with like-minded families creates opportunities for a unique kind of support and a sense of belonging and acceptance that is not always possible in a world where we seem to continually have to explain our children, advocate for them or be 'realistic' about our dreams for them.

As a young mom, I rallied like-minded parents in my community into a group that did 'what it took' so that our children could participate in community recreation programs alongside non-disabled children. Our group met monthly to talk about the challenges each of us faced, shared knowledge gained from our experiences and helped each other figure out solutions. We connected parents to community resources, supported each other's child at sport activities and celebrated together.

Throughout the years I have also participated in training events and conferences organized by the provincial and national association for community living that provided opportunities for relationship building with families from around the province and across the country.

*Continued on page 2*



Canadian Association  
for Community Living

Association canadienne pour  
l'intégration communautaire

Diversity includes. On se ressemble.

## cont... The importance of connecting

Dianne Cormier Northrup

I met some amazing parents who helped me expand my vision of what is possible for my children and had a large influence on who I am today as a mom and a person. As a plus, I developed some precious friendships that are near and dear to my heart.

Today we are seeing the traditional face-to-face meetings families formerly used to connect with each other, being replaced by social media. Through Facebook, personal blogs and other social media formats, families young and old, are connecting with other families from across the country and indeed around the world. Families are developing their own community of followers or support networks. They use social media to talk about their children and share the stresses affecting their lives. They feel for each other, laugh, shed tears and offer each other

tangible practical information on how they have dealt with daily challenges. Families are also learning how social media reaches out to the broader community, providing them an inside look at the struggles and dreams of families who have children with disabilities. They are learning how powerful social media can be in informing and influencing... becoming one more avenue in helping our communities become more inclusive places.

In this edition of *Coming Together... to Create Change*, we feature stories about how families have connected to other families, and the impact of these connections on their lives and that of their sons and daughters.

Sincerely,



## We are rocks because we are not islands

Angela Loeppky, Manitoba

blog: "Life in the Special Lane" <https://byronang.wordpress.com/>

There I saw him. At our local aquatic centre. A beautiful little boy. He was jumping up and down by the kiddie slide, my gut somehow told me it was in anticipation of being knocked down by the children sliding. I shouted out to him, "Excuse me! You should move! You're going to get knocked over!"

The boy appeared deaf and did not respond to my cautions. Instead he smiled a huge smile and jumped up and down flapping his hands. I caught his mom's glance indicating everything would somehow be all right.

Additional to my concern for

this little boy strangely came an overwhelming high. I had never EVER seen, heard of or read about anyone like this before ... except in my own daughter.

Hannah was born healthy. However at 2 months the whirlwind of Hannah's life began. A cough turned into pneumonia and a heart murmur was detected. She was inundated with continued chest infections, a weakened immune system, heart surgeries and procedures and a plethora of doctor visits and specialists to help us raise Hannah and get her healthy and to our final goal – to keep her healthy.

During these fearful years, to add insult to injury, her behaviour was severely "off" and she was not developing. "Not to worry" we were told ... "She's been through a lot – she'll catch up". But deep in my heart I knew something big was "wrong" with my baby. She had no skills and was not reaching any milestones. In fact she appeared deaf – yet we were perplexed. Why couldn't she respond to her name as we (cautiously) shouted it by her ear, yet would run to the kitchen (a number of rooms away) when she heard a bag of chips being opened?

Additionally to the lack of

relationship with us, her debilitating behaviours ran hers and our lives. All day laughing fits would start at seemingly nothing and continue as she fell to the floor crashing her head. It was unreal, confusing, terrifying and isolating for us. And yes bitterness and anger soon took over in my own life.

The eventual Autism Spectrum Disorder (ASD) diagnosis meant that there was finally a treatment plan. We immediately enrolled her in the Applied Behavior Analysis (ABA) program.

While the diagnosis and treatment plan that led the way to Hannah fulfilling her own true potential was life giving to us, the fact that she had autism continued to be extremely difficult. What did we know about autism? Rain man? We knew very little and Hannah's autism presented very differently than anyone we knew with ASD. Any social group, any interactions with typical moms with typical learning children felt isolating and lonely. I knew the intent of people was good but it felt like no one got it. Our life was like living on Mars while I jealously watched Earthlings.

But with hard work we saw Hannah meeting her own true potential.



That little boy jumping by the kiddie slide? Years later I re-met his mom at an ABA meeting. Once we got to talking about how our kids were 'the same', the conversation flowed and a natural connection was immediately there. We continue to be great friends to this day!

Somewhere in those later years (age 13 for Hannah) computers and the internet became available and we found each other. Other moms ... like me! My autism moms and sisters.

Through private social media we have each other. We got each other's backs, we are there for each other and understand difficult days, unnerving appointments, frustrating meetings, we rejoice with each other when our children achieve

goals that would be miniscule to the typical learning in society – but WE UNDERSTAND! We laugh and we cry and we support each other in real ways. Because we get it.

What happens when one feels isolated? Strength is depleted. Feelings of hopelessness overwhelm. However, when we have each other and can know that we are not alone – that there is a society of like-minded (in our case) moms who we know care for each other and, more so, care for each others' kids, strength grows. And when we feel strong we can be there for kids – to help each of them meet their own true potential. Who doesn't need and want that?!



Diversity includes.

# You think you're the only one

Normand McDonald, New Brunswick

By Christy MacLean, NBACL

Many senior parents of adult sons and daughters with an intellectual disability share common experiences, but for parents like Normand McDonald of Fredericton, New Brunswick, finding other parents to connect with was a difficult and frustrating experience. That is until he was connected with SUN NB, a network for parents of adult sons and daughters with an intellectual disability.

"I knew there was something out there, but I didn't know what, or where to find it," says McDonald, who has an adult son with an intellectual disability.

He decided to call the New Brunswick Premiere's Council on the Status of Disabled Persons who connected him with the New Brunswick Association for Community Living (NBACL).

McDonald was introduced to NBACL Family Support Facilitator, Julia McCluskey, who told him about SUN NB. Members of the network meet once a month in a casual setting to share their experiences, support and laughter.

"I called Julia and instead of waiting for the next SUN meeting, she connected me with another father from the

network, who also had a son with a disability," McDonald says. "After my very first meeting with Julia, I walked away feeling ten feet taller, because I felt that a big weight had been lifted from my shoulders," says McDonald.

"I didn't have to wait forever."

McDonald says his first SUN meeting was a positive experience. He felt welcome and was impressed by the wealth of knowledge around the table and how many connections he made with other parents.

"I was surprised that there were so many other people like me. You think you're the only one," says McDonald.

Occasionally, SUN NB invites guest speakers to share information on issues such as will and estate planning and supporting adult sons and daughters to transition into a home of their own.

"I learned about the Social Inclusion program and for the



first time, I talked to my son about finding a home of his own," says McDonald.

"Now he's really looking forward to it and is talking about it more."

McDonald says he feels gratitude to the parents who blazed the trail so that his son and others can have access to supports.

"A lot of what we have today is because of these parents, mostly women who had nothing when their children were young, so they had to create these things," he says. "I have a great deal of respect for them."

"There is one word that drove them," says McDonald, "And that word is love."



Diversity includes.

## Want to learn more or get involved?

CACL.ca provides a place for families and people with intellectual disabilities to connect, share, network and learn from each other.

At CACL.ca you can:

- **Subscribe to our e-newsletters** for more in-depth information. In addition to *Coming Together... to Create Change*, CACL publishes four newsletters to help families and community leaders fight for inclusion: *Inclusion Matters*; *Education Watch*; *Institution Watch*; *Poverty Watch*.
- **Create a profile at CACL.ca** and connect with other members of the community living movement and join the conversation by commenting on blog posts and stories.
- **Share your story** — At CACL.ca you can share your story and read about other's real life experiences as inclusion champions in their lives and communities. Connect and learn how to push inclusion forward.
- **Follow our blog** for all the newest information on CACL and the community living movement—information that can empower you to advance inclusion in your own circles.

Families who are informed about and committed to human rights and inclusion, knowledgeable about inclusive practices, and who have high expectations for their family member are the most powerful advocates and drivers for inclusion of people with intellectual disabilities.

Do you have more ideas for advancing inclusion in your community? Suggestions for tools and information that would be helpful? Have a success story or tip to share? Tell us! We'd love to connect with you! Email us at [inform@cacl.ca](mailto:inform@cacl.ca).

## It takes a community

Nicole Martin, Alberta

My daughter, Gabrielle, plays baseball and other sports. I remember watching one of her practices when she was seven years old; they were practicing running bases. As Gabby approached second base, she started slowing down, but cheers of, "come on, Gabby!" from her coach and teammates filled the air until Gabby made it all the way to home plate. For our family and the other families involved, baseball is more than just a sport. Community

engagements, like baseball, are places for our children, and really the whole family, to build meaningful connections in an inclusive community.

Before becoming part of a network of families, I remember focusing on Gabby's disability, Down syndrome, and her medical needs. I made every effort to ensure Gabby received all the therapy she needed. However, this resulted in Gabby and I becoming very isolated, even

from the rest of our family, since so much of our time was devoted to appointments and carrying out therapist directed activities. I had thought our family might have to move from our small Alberta town of Mallaig, into a big city in order to access the right resources and education for Gabby. In the beginning, I could only imagine Gabby becoming friends with other children with Down syndrome, and being educated in segregated classrooms.

## cont... It takes a community

Nicole Martin



When I first joined one of Inclusion Alberta's family networks, I was the youngest parent in the group. This gave me the opportunity to hear stories from other parents who had adult sons and daughters with developmental disabilities and about the possibility of an inclusive life.

I later attended an Inclusion Alberta Personal Futures Planning workshop with Connie Lyle-O'Brien. I invited about ten of our friends and family members to participate and in continuing to learn about the promise of an inclusive life this event became an important turning point in our journey.

I began to think about the exciting future that Gabby's life could hold. I became committed to advocating for Gabby's right

to be educated in an inclusive classroom. With the help of Inclusion Alberta's advocacy and support, Gabby's school is now a place where she is learning academically and engaged in meaningful relationships with her peers.

More recently, I was invited to participate in Inclusion Alberta's Family Leadership Series over five weekends, and this encouraged me to broaden my leadership role in our community. Our local family network evolved into a formal local association, called Inclusion St. Paul, and I became an Executive Committee member. My passion for supporting families and partnering with the community, in order to create meaningful and inclusive lives for our sons and daughters with developmental disabilities, led me to become the chairperson of our inclusive education working group.

Gabby is now nine years old, and her life exemplifies the work and vision of Inclusion St. Paul and Alberta. Not only is Gabby fully included in her

grade four classroom, but she is also engaged in her school's homework club, our church community, the agricultural society, skating, gymnastics, and baseball. It has been wonderful to see Gabby make genuine and meaningful friends in all the different areas of her life!

What I envision for Gabby's life in the years to come includes many transitions: junior high is only a few short years away; then there's high school, possibly university or college; and eventually a career. It's nice to know that through Inclusion St. Paul there are families with older children who have managed some of these upcoming transitions, and are now mentors to our family as our journey progresses. There are also younger families who are part of Inclusion St. Paul. I understand the fears younger families face, and I know this can limit what they envision for their sons' or daughters' futures. Now I can mentor them by sharing our journey, the expansive vision we have for Gabby and how she now has a full and rich life. My work with Inclusion St. Paul and the families in our community is fueled by my belief that, like Gabby, every child deserves the right to belong and live a meaningful life in our community.

# Inspired by a child

Patricia Franks, Ontario

In 1988 a child was born who changed the lives of those who know her. She brought people together. She made people work harder. She inspired laughter and love, caring and hope, family, friends and strangers. There were struggles and disappointments. This child, now an adult, made herself part of whatever she was given the opportunity to be involved in. The important part for us as parents was making the opportunities happen. That took the whole village.

This is the story of a real person. My name is Patricia and my daughter Gabi, youngest of three, pushed us into a new way of viewing the world. There were tears and struggles, loneliness and frustrations, but this did not take away from the love and determination which we as parents were shown by our special child.

As parents we sought and found families in similar life situations. We began to appreciate the need for sharing our experiences, our stories and our energy with other families. Equally important, there was the need to share all these with the wider community. Through the involvement in, and the assistance of various Community Living organizations, and the support from other families, we found our way through the early years, the school



systems and into the void of after 21.

In 2011, Community Living Ontario piloted a special retreat series which gave a few families from around the Province an opportunity to share and learn from each other. From this inspiration I found my voice as an advocate and our community support network was born. Caledon Area Families For Inclusion (CAFFI) was founded by families to support each other and to advocate to the wider community. It was especially dedicated to our over 21-year -old family members.

We are not interested in adding another layer to the bureaucracy so we are not formally registered. We have connected with our local Community Living, Community Services, Church, Municipal and Regional Government groups.

This allows us to advocate for a housing strategy with the town and involvement opportunities for our young adults. Social opportunities for our young adults have been established through the month where parents share the load while the adults learn social and independence skills. Our monthly meetings give us the opportunity to share the stories and progress, the setbacks and the solutions. We are engaging, one person at a time, the whole village, so as our children grow up and grow old, they will always belong.

We as parents can never hope to tackle all the challenges by ourselves. It is in gaining strength and support from each other that we become strong enough for those who need us most. Our special children, who are needed to show love to the world.



Diversity includes.

# How making real connections can change everything

Laurie Frandsen, Ontario



My name is Laurie Frandsen and my husband Andrew and I have two amazing children, Hannah (16) and Adam (14). I am an educational assistant currently employed as family engagement coordinator for Community Living Ontario and Andrew is a self-employed carpenter. When our son was about six months old our family started the long journey into the world of agencies, diagnoses, therapies and strategies. We were lost and confused and wanted answers.

Not knowing why you have a child that doesn't act like all the other children his age or like everyone says he should act,

drove us deeper and deeper into the disability world looking for help and somewhere to belong. Friends and family showed concern by offering sympathy and comforting words when we needed, but few offered a safe and welcoming place where our son would be loved and accepted without any explanation. My husband and I felt it was our job to be constantly at our son's side to explain to anybody with a sideways glance, why he did the things he did. This fear of judgment made inclusion in the community difficult. Whenever a social activity or school placement didn't work out,

and they usually didn't, we let our son stay home and do 'his own thing' hoping that it would make him happier. Over the years we consistently invited our son's class/church friends over but unfortunately as each year passed the gap between the other kids and our son grew.

I wish I could say that it was my idea to reach out to other families because I knew it was the right thing to do and exactly what our family needed, but it wasn't. A very good friend of ours invited our family to a weekend away to relax, listen to a great speaker and meet other families that had a loved one with a disability.

We had no idea what we were getting into or that this one weekend would turn into several weekends over four years. The speakers that we met over the years were inspirational. My husband and I found ourselves thinking about disability in a whole new way...a way that didn't make us feel ashamed or alone. For the first time in our son's life we understood that the disability Adam faced was the one society created for him. But even more importantly than the information we received from guest speakers, were the connections we made with other families.

Even after the very first weekend we went home with a renewed feeling of strength and energy. Hearing others talk about their struggles and their successes, crying and laughing with them, opened up a sense of belonging in our family that we had never felt before.

Bringing this sense of belonging back to the community has been the real challenge. My husband and I, along with another family, have been part of a family engagement project in Welland for two years. We have offered both formal and informal events for families to take part in. Because we know

first-hand the benefits of families being together and sharing their stories, we have persistently called, emailed and sent letters to families inviting them to be part of a conversation with us and with each other. Connection and a sense of belonging don't happen overnight. Many families dealing with a disability have put a lot of effort into keeping their loved one safe for a long time. Convincing them to open up to and trust others has been hard to do...but not impossible...small steps are being made!

I wish I could say that getting together and connecting with

other families has solved all of our problems but it hasn't. But what it has done is show us that we don't have to try to figure everything out on our own. We found a community that accepted all four of us not only for the mess we felt we were, but for the family we wanted to be. We get inspiration, hope and strength every time we connect with another family and I strongly encourage all families to seek out and connect with people that can give them this. If only we had known earlier in our son's life how much richer all our lives would be by making real connections like the ones we have now...well it's never too late!

## Do You Have a Story to Share?

*Coming Together...to Create Change* is a family newsletter about families helping other families through the sharing of stories and experiences. Stories of how families have faced and overcome challenges at a variety of different levels as they have created lives of inclusion for themselves and their sons and daughters.

If you have a story to share we would love to hear from you. To submit a story you can contact your provincial / territorial Association for Community Living, or contact either Dianne Cormier Northrup at [dianor@rogers.com](mailto:dianor@rogers.com) or Don Gallant at [dgallant@nl.rogers.com](mailto:dgallant@nl.rogers.com).



Diversity includes.

# A National Family Leadership Series

As part of the Canadian Association for Community Living's Coming Together... to Create Change: National Family Leadership Series, CACL, in collaboration with participating Provincial/Territorial Associations for Community Living, is offering its Values, Vision and Action Workshop. The Values, Vision and Action Workshop is a weekend retreat provided to groups of 20-25 family members.

The workshop is highly interactive, consisting of individual and panel presentations, small group sessions, and a variety of informational videos. Participants will gain a deeper understanding of the history, values and vision of the community living movement, the changing perspectives on disability within our society, and the role families can play in translating this vision into a 'good life' for our family members.

Families' values, vision, passion and commitment have inspired and led this movement for over 60 years. The purpose of the leadership series is to share our values and vision and to provide resources, support and tools to assist families in imagining change, pursuing it, connecting for social change and leading the way to inclusion.

## Why Participate in the Values, Vision and Action Workshop?

- To imagine a good life for our family members and a world where we are recognized and valued as part of the diversity of our communities.
- To explore the power of families and family leadership in changing how society sees, understands and accepts disability.
- To develop strategies to put our values and vision into action.
- To build the strength of family-to-family connections as the foundation of our grassroots movement for community living.

**"I recommend everyone possible to attend. This type of workshop is life changing in a most positive way."**

*Workshop Participant, Maple Ridge, BC*

## Values, Vision and Action Workshop in Your Community

If you have a group of families and are interested in finding out about having a workshop organized in your community please contact CACL at [inform@cacl.ca](mailto:inform@cacl.ca) or 416-661-9611 ext 227, or your Provincial/Territorial Association.



Canadian Association  
for Community Living

Association canadienne pour  
l'intégration communautaire

Diversity includes. On se ressemble.

Follow CACL on social media!

