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Coming Together is compiled and produced by the CACL Family Leadership and Volunteer Engagement Advisory Committee to highlight the power of families to effect change and advance Inclusion.



## Message from Barb Horner, Chair

As I began writing this editorial, my mind was flooded by many fond memories of CACL when I was first introduced to this grass roots family movement over twenty years ago. I will never forget attending my first national conference as a young, timid parent and finding myself in a room surrounded by family members and self advocates who shared the same values and goals of social inclusion and equality that I held dear to my heart for my daughter, Mallory. It felt like coming home—that I finally belonged and was understood. More importantly, my parenting ideals were never called into question. In fact, connecting, learning with and from other parents over the years has been one of my greatest inspirations. Other parents who have walked the path before me have been my teachers and mentors. We have much to learn from each other's past experience,

wisdom and skills that we gather along the way. Indeed it is this connecting of families, this 'coming together' that is so important to maintaining the passion within the community living movement.

I have been involved with my provincial ACL in different capacities over the years and have had many learning opportunities at the CACL level. I feel so fortunate to have been able to attend national conferences, sit on committees and task forces, working hard with other parents and self-advocates to keep our agenda public and political. The more I learn, the more Mallory benefits—it has a positive impact on our entire family and ultimately our community, as Mallory forges ahead with a presence and belonging in her city.

For me, it is when I am surrounded by families, friends, self advocates

that this movement truly comes alive. It is when I am reminded, when I know, that my family is not alone. There is both comfort and excitement in that feeling.

Our ACL federation was begun by groups of families sitting around their kitchen tables talking about a better life for their sons and daughters. Dreams turned into reality and families have become leaders and advocates on a national, provincial and local level. It is astounding what families can accomplish when we come together with a united voice. We are a powerful force and unstoppable with our passion, commitment and empathy for each other's lives.

In this edition of Coming Together we features stories of how families from across this country are able to stay connected and draw strength from that connection, in whatever form it takes. Enjoy.

# Allowing Families to be Families First

By Christy McLean

Developing family leadership allows families to have stronger voices at both the community and provincial level, specifically around issues that families encounter when supporting a loved one with an intellectual disability. NBACL has formed a Family Support Task Force to ensure that families are empowered with information, resources and connections to other families.

“It allows families to be families first,” says Dianne Cormier Northrop, Vice President of the New Brunswick Association for Community Living and Chair of the Family Support Task Force for New Brunswick.

The Family Support Task Force ensures that there is a grassroots presence of empowered families and family leaders in the province of New Brunswick. The task force works

on family leadership, advocacy and in developing regional and provincial networking opportunities.

The purpose and goals of the Family Support Task Force are: To assist in providing strategic direction to the provincial Family Support Program; Ensure a voice for families and create healthy networks and connection for families of persons with an intellectual disability; Engage families and share information in members’ regions; Research and develop an ongoing sustainability plan. A goal of the Task Force is to have representation from each region of New Brunswick, one of which will serve on the provincial Association’s (NBACL) Board of Directors.

Engaging families at the grassroots level is a key part of the mission of the Network.

As such, they have established two networks, the Families United Network (FUN NB) and the Seniors United Network (SUN NB). These networks are geared to provide families with

peer support and information that is relevant to them along each milestone of their family journey. SUN NB is similar, but also addresses unique issues related to aging families.

Getting the word out about activities and new information is also an important aspect of the Task Force’s work. The Task Force plays an active role in sharing information around new policies, supports or issues that will affect families. They do this via Facebook (social media) and by publishing a quarterly newsletter.

The Family task force also hosts retreats and other gatherings to give families opportunities to share information, stories, support and lots of laughter with other families who share similar experiences.

In March of this year, NBACL held a parent retreat on Inclusive Education in Moncton. The following is a letter by parent, Shanell Mouland of the popular blog [www.goteamkate.com](http://www.goteamkate.com). Shanell and her daughter, Kate received international attention from a blog that Shanell wrote, “Dear ‘Daddy in Seat 16c.’ You Had Me at ‘Retreat’ is a message written by Shanell to NBACL after she attended the event. It is reprinted with permission by the author.





*First of all, to the members of the NBACL, you had me at “retreat”. When the email inviting parents of children with disabilities to attend a ‘retreat on the province’s inclusion practices’ came across my desk I was immediately intrigued. Their choice of vocabulary was obviously alluring but a chance to look at this policy surrounded by other parents for whom it is crucial was equally as enticing.*

*I suppose I should share a little background. I am a resource teacher and have spent much of my time on the ‘other side of the table’, so to speak. The new inclusion policy is integral to my professional life as well. I also have a three year old little girl with autism. I write about her on my blog, [www.goteamkate.com](http://www.goteamkate.com). So, you can see, I have a very unique perspective when it comes to the implementation of such a policy. I firmly believe the education of families about this policy is paramount. Clearly, the NBACL feels the same.*

*The ‘retreat’ as it were, was held just minutes from my home. I emailed the organizer to reluctantly admit that my husband and I did not need a hotel room for the evening. Her response was to kindly offer the room, anyway. Of course, with a child with autism, we rarely sleep through the night and getting up before dawn is common. This*

*kind soul offered us a chance to get a good’s night’s sleep and some respite before sharing with other parents our ideas and concerns regarding the policy.*

*We dropped our children off with Grandma and headed to the hotel to enjoy the keynote speaker, Michael George. As this father spoke of his family’s experiences with the system and his twenty one year old son, Ben; who might not have lived beyond his first 24 hours, and now attends UNBSJ, we were riveted. His story was heartbreaking and hopeful and inspiring just like so many of yours. We were privileged to hear it.*

*My husband and I went back to our room to chat about the evening and prepare for the next day. We talked with other parents on the way out and we all had one thing in common: we were all looking forward to uninterrupted sleep. I’ll add that I was also looking forward to a ‘Disney Junior’ free evening and drinking nice wine from a proper glass.*

*The next morning, I kid you not; we slept until 8:15. We haven’t needed to use an alarm in years. We were shocked to wake so late*

*and quickly got ready to head down to breakfast. The day would start at 9:00am which is a most civilized time if I ever saw one.*

*We listened to presentations and collaborated with parents in like situations and all the while we were making connections and friends that will forever be useful. We dug deep into policies written for the protection of our children and we had experts (and by ‘experts’ you know I mean the parents of children with disabilities) right there to help walk us through. It was a day of excellent presentations from various members of the NBACL on various topics surrounding inclusion. Their easy-going style allowed for discussions that would involve the entire room. Well done NBACL!*

*I am grateful for the chance to have participated in this event and hope to be a part of many more in the future.*

*Shanell Moulard*



Diversity includes.

# Caps, Snaps, Songs and Sundry Other Connectors

Dennis Gill

The process of family connectivity may sound simple, but it may be quite complex for many who have a member with an intellectual disAbility, depending upon a diversity of factors. “We All Are Different”.

For over half a century the Newfoundland & Labrador Association for Community Living has been engaging and connecting families quite successfully via meetings, forums, conferences, phone calls, face-to-face conversations, newsletters, awards of recognition, the web site, linkages with Associations for Community Living across Canada, including CACL, to mention a few.

For over three decades the Gill Family of Pilley’s Island, NL, has utilized varied methodology, but not really anything that we would consider innovative. However, we will forthrightly share some of our strategies and thoughts on how we have “expanded our boundaries” with a view that they may be helpful to others.

First, a succinct family background. I am a retired high school educator and administrator, and since 2003, an Executive Assistant for a company which operates provincially. My wife Roxann, a retired Hairstylist, is currently a Homemaker. We are the parents of two children, Daniel and Jenna.

Danny was born “perfectly healthy and normal” on 09 June 1980, but developed frequent epileptic seizures, petit mal and grand mal [the latter still persist to this day], after his initial immunization

at three months, which lead to subsequent severe developmental delay both intellectually and physically. Though Danny cannot walk or talk, and is totally dependent on us and others for his many needs, he has truly blessed our nuclear and extended family, and for over years has taught us to be better human beings by way of caring, sharing, loving, and compassion, to cite just four traits. We have been “down the disAbility road” in the real world. But, we have kept a positive attitude, dealt head-on with the various challenges which have beset us, and strived to make the best of a situation created beyond our control.

Jenna was born on 06 May 1986 and convocated from Memorial University of Newfoundland in 2009 with a Bachelor of Commerce [Co-op]; she is employed in St. John’s as a Cost Controller with Seadrill, an international oil company. Ever since she was a little girl, Jenna has loved Danny dearly, has helped us tremendously with his care, has been extremely protective of him, and has been very, very responsible.

Roxann and I lovingly and particularly care for Danny, 365 days annually, twelve hours per day, down from twenty-four hours in the years pre-2002. We live by a regimen which consistently features an 8:30 pm curfew! By choice and design, we have hired three part-time Respite-Attendant Care Workers for 168 hours bi-weekly, courtesy of the NL government Department of Health & Community Services

to whom we are most grateful. For eight hours daily, Danny is taken by his worker, from his own apartment in our home, by vehicle or wheelchair, to her home, weather permitting.

[During the dozen years of this arrangement, there have only been seven workers and they have all been excellent, without exception; a big plus for outport Newfoundland & Labrador. Two have retired from the workforce, and two re-located because of their spouse’s employment and health, respectively.] Each Respite Family has friends and relatives in our historic and picturesque community of 300. We conservatively estimate that Danny has connected directly with around a score of families who have all come to embrace him; indirectly, of course, we know every single family in town!

Danny has been wearing caps since he was a small boy. We started hanging his caps in his apartment during recent years. His collection grew slowly and steadily. The head-wear came from families, friends, acquaintances, companies, organizations. Danny has a cap from the Bahamas, RCMP, Canadian Idol, Houston Astros, NAV Canada, Churchill Falls, NTV, Pepsi, and his one hundredth from London, England ~ a memento from sister Jenna’s visit there in 2013. They are triple-c: connectors, a conversation piece, and a collection in which others can participate and become engaged. Avid amateur photographers since 1977, Roxann and I have

clicked the old Pentax and new Canon thousands upon thousands of times. The pics on the front covers of CACL's National Report Card [December 2013] and Coming Together [Winter 2014] are ours ~ GillPhoto. Plus, CACL has many more of ours in their library. Numerous shots on the website of the Newfoundland & Labrador Association for Community Living, [www.nlacl.ca](http://www.nlacl.ca), and in its publications, initiatives, and promotions were snapped by GillPhoto. Photos are a tremendous tool for engaging and connecting families.

For the past seven years we have been designing and printing our own Christmas cards which feature family activities during the previous twelve months, and our own verses. Each December we enter the homes of 108 families in NL, across Canada, and to the USA. Then, there is Facebook; check out Roxann Gill. She posts carefully selected photos of Gill Family pursuits and inclusive events like birthdays, boating, cod fishing, trailering, Canada Day Celebrations in Pilley's Island; all of the aforementioned enhance personal linkages.

Last, but by no means least, is music. That is by far Danny's greatest enjoyment in life. He absolutely adores music videos of such artists as Raffi, John Fogerty, Neil Diamond, Lori Morgan, Great Big Sea, Olivia Newton-John, Queen, John Prine, Jenna, and

the list goes on and on. I am a self-taught guitarist and song-writer; since 1970 I have written well over one hundred originals.

Several I sing for Danny, especially this one entitled, "We All Are Different", which I wrote for him when he was only six years old:

*We often take for granted the things we do each day,  
Like walkin' and talkin' or the many games we play,  
To us they are so natural that we may not realize*

*How fortunate we really are to be free and fit and wise.*

*Let's stop - and look around us from a different point of view,  
At loved ones with "differing needs" who find some things hard to do;*

*The distinct problems that they have may not be plain to see,  
But remember they're a part of this great big family.*

*Chorus*

*We all are different, some more, some less,*

*One person's strength is another's weakness;*

*We're all a part of God's Master Plan,*

*At times we all need a helpin' hand.*

*So next time you see someone little bit different from you,*

*Please won't you try and understand what they might be going through;*



*Their challenges may not be yours, but yours may not be theirs,  
Practice the Golden Rule, it will help lessen their fears.*

In conclusion, during the past 30+ years, we have witnessed marvelous improvements in the ways which families can connect with other families whatever the situation or geographic location.

Enhancements in education, technology, communications, transportation, medical knowledge and facilities, accommodations for families while attending appointments away from home, better systems of support, sustained advocacy, all the way to the UN Convention on the Rights of Persons with Disabilities. And there, "standing on guard" with families, is the Canadian Association for Community Living, and its P/T affiliates, right across "our home and native land".



Diversity includes.

# familyWORKS

Aaron Johannes, Director, Spectrum Consulting

In Vancouver, the familyWORKS group has been meeting for about 18 months. That particular group has decided that there will be different speakers and panels each month, alternating between family members telling the stories of their children and siblings' employment and various professional panels who answer questions about process.

The initial proposal read that "familyWORKS' is about shifting attitudes. We will work with families to feature/show what is possible in terms of employment. Our goal is to identify, acknowledge and work through those family barriers to employment options."

Our social enterprise, Spectrum Consulting, met with familyWORKS to conduct some strategic planning sessions over two sessions a month apart –

approximately twenty families came each time to share their ideas about future directions and what would be helpful supports. Consistently, the idea of peer support from families and being able to create and share a transparent process for how families could access supports came through loud and clear.

BC's current energetic focus on "Employment First" has been visionary and progressive but for many families who have had to spend much of their lives functioning within deficit based models to access supports and services for their adult sons and daughters, learning how to shift their thinking about employment for persons with developmental disabilities happens best by sharing the employment experience and expertise of mentor families.

Other families are already hungry for a chance to talk about asset based thinking about their children and siblings. One mother said that after twelve years of attending school meetings to constantly remind them of her son's gifts, year after year, when they wanted only to focus on his deficits, she was surprised when a job coach came in and said that he would now take over and had no questions for her. "I know him best, I know what he has to contribute, and it's a waste not to use information I've spend so long thinking through and collecting." Another mom talked about her child being supported in a new job development program to create a resume: "It's his 34th resume and he has yet to be paid for any work he's done – do people even use resumes any more? The people benefiting from those

34 resumes were the people who supported him to write them, most of the time without even referring to the last one."

As far as we can see, the familyWORKS model, originally developed by parents, is singular around the



FSI Training Weekend - April 10-13, 2014

world. It functions as a kind of job club for the behind the scenes allies of the job-seekers. Families connect with government supports, employers and others and ask questions about processes as well as give input. Like B.C. self advocates who say of this new focus on work that they “want to be at the front of the room,” parents too are concerned to seize the opportunity to be part of conversations they feel they’ve too often been left out of.

“familyWORKs” chapters are now expanding to three more regions of B.C. and organizers are thinking of these as “Learning Labs” to ensure that local groups have a space to develop processes and methods that work for them in terms of engaging in dialogue about steps taken during job finding and supporting processes, as well as establishing strategic approaches to capture and share all learning.

The strong family based knowledge of the B.C. Family Support Institute brings a more holistic approach to this project. FSI is in a unique position to support families and their loved ones to develop a vision and action plan regarding employment opportunities.

Angela Clancy, Executive Director of the Family Support Institute says that, “At FSI we believe families are the experts when

it comes to their sons and daughters and we are heartened to see that CLBC is committed to investing in families with this in mind as well. We are pleased to expand our work with families to identify internal and external barriers to employment, validate their experience and concerns, and assist them to come to a new place of seeing and exploring what is possible for their sons and daughters. This partnership with CLBC has allowed us to do this, and for that we are grateful.”

Each month in the Vancouver group parents get to hear about new ideas they may not have considered – one night when we visited, a mom was talking about developing a family business over her son’s lifetime because she envisioned him working as an adult, despite the expectations of those around him, and everyone in the business was prepared for his working there. On the same evening, a mom was sharing some tips on how she had supported her daughter to apply for jobs in a world where most applicants have to go online and fill out forms.

Last month families talked to a panel of parents and children who have started small businesses, and shared information some of them had brought back from a recent workshop on micro-business



start-ups for people with disabilities. The previous month featured a panel of employers talking about why they wanted to hire and work with people with disabilities and the gifts that they brought.

“I want,” said one of the mothers during our planning session, “the community to finally see my daughter as a person with gifts who has contributions to make. I believe there’s a perfect job out there just waiting for her, but it’s helpful to get together and talk with other parents about how to support that process.”

Our agency is very interested in alternative approaches to how people might find and keep jobs that matter to them. Through a project, Alternative approaches to supported employment, we’ve been exploring how they might tap their networks, given that so many of us find our work through friends and family. We believe the familyWORKS initiative is one of the most exciting and innovative projects in B.C. and are glad to have a chance to get to know their work better, and to see them expanding in influence.



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# The Sharing Circle – Engaging and Supporting Families in Manitoba

In the fall of 2013, Community Living Manitoba launched a new way of supporting families in our community. Called “The Sharing Circle” this initiative brought together mothers and grandmothers of people with disabilities from Winnipeg and the surrounding areas. The Sharing Circle is an aboriginal tradition where, after participating in a smudge, those gathered around take turns speaking and listening with the help of a “talking stick.”

The ten week program was set up to cover a variety of themes and included one hour of yoga followed by the sharing circle. Our 10 themes were taken from the 10 ethical principles of the yogic tradition that allow us to be at peace with ourselves, our family and our community. They included: Compassion for

All Things, Commitment to the Truth, Not Stealing, Merging with the One, Not Grasping, Purity, Contentment, Burning Enthusiasm, Self-Study and Celebration of the Spiritual.

Gail Gagne, from One6Yoga, introduced each theme as our participants transitioned from their busy and stressful lives into a more relaxed state. The group facilitator further explored each theme as they gathered in a circle afterwards and searched with them for the relevancy of each theme in their lives. We were also guided by a local aboriginal elder who was participating in the program as a caregiver (serendipity at work!). Those who participated benefited from the sharing of joys and sorrows, learning from each other and learning how both the yogic and aboriginal

traditions can be incorporated into their lives to bring a sense of serenity and strength.

Due to inclement weather, the 10th session for the group was postponed until early spring 2014, but plans are already underway to begin a second sharing circle program. The combination of self-care and sharing of experiences and understanding with this program seems to bring a greater sense of community for those involved. We hope and trust those who participate in this program will carry that sense of community with them as they continue their life’s journey. We also hope they will be like ripples in a pond, spreading their gifts and talents with others whose lives they touch, and helping other caregivers of people with disabilities along the way.



50 years

Canadian  
Association for  
Community Living

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Follow CACL on social media!



Connections, we make them every day.

We have created a life full of links to persons, places, pets, and comforts ~ that we value and treasure. We are connected to our family, children, friends, neighbors, and coworkers. We are nurtured and sustained by our connections to those who support us, guide us, encourage us, educate us, feed us, build us up and stand with us.

There is no denying the power of connections. Your day feels more productive when you know you have forged a link that connects you to your goal. Being able to connect to families or individuals who are supporting a person with an intellectual disability has always been a vital link for PEI ACL. The family networking that has happened over the years has not only served to strengthen PEI ACL's awareness in the communities, but has allowed for family connections to occur.

There is something very powerful in the often learned knowledge that you are not walking a path alone. When a family is looking for support, information, and encouragement, it will, in most cases, turn to another person who understands the struggles, day to day concerns, worries for the future for our sons & daughters with intellectual

disabilities.

The line "someone who has walked the walk" has real depth and meaning.

With the necessary move to the more technological world of social media, we have been learning a lot over the last year as to how to support families on line.

PEI ACL formed a steering committee last spring, of committed family leaders. This group consists of 5 amazing women from various regions of PEI, as well staff support. Some are Moms, a Grandmother, and a dedicated Early Childhood Educator who are supportive of our movement to an online family network for families in this 2014 year.

They have all agreed to stay on as family leaders in this next phase of work and to connect to and identify, other families that live in their communities, go to their schools, or who they know in connection to similar family circumstances. They are yet another link for strengthening the connections of families across the Island.

The commitment of these leaders will be essential to the formation of our on line Blog, and other online media outlets for families

to access. PEI ACL is creating a new website, that will offer the family network a button to link to the blog.

In this blog we will have information for families in the areas of family & disability supports, and inclusive education, as well as an area to post concerns and ask questions. A calendar that will be posting upcoming webinars, conferences, resources, guest speakers will be on the blog for families to access and the family leaders will be connecting families in their areas with the blog, and each other.

We will also have a Facebook page for families to be able to ask questions & get support that they need in the everyday navigating of the system.

Another stream will be the twitter account that is already set up, as well as a Youtube channel that will be a compilation of videos around the priority areas. All of these streams will be accessible by buttons on the blog.

There is a real Power in the shared connections that will come from this new move into the online world. I look forward to it. You can follow the family network on twitter: [juliesmith@peiaclnetwork](https://twitter.com/juliesmith@peiaclnetwork)



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# Engaging and Connecting Families

Over the past few years NSACL has been, through our Community Inclusion Coordinator, reconnecting with families through hosting a series of meetings throughout the Province.

The feedback and participation of families has been quite incredible as has the partnerships with groups that NSACL has had little involvement with in the past such as L'Arche Cape Breton, Mawi Ta'mik Society and Family Resource Centres.

It is quite exciting to become more involved throughout the Province, listening to family's stories, their concerns and their dreams for the future. NSACL has been actively



involved with government in developing the new “Roadmap” for Transforming the Nova Scotia Services for Persons with Disabilities Program. “Choice, Equality and Good Lives in Inclusive Communities” is all about how services are delivered to persons with disabilities and how people should be supported. IRIS facilitated this process with a committee comprised of government, various disability groups and self advocates.

It is the first time in a long time that families have had hope for the future of their family members with a disability. Supports will be person planned and centered, funding will be individualized, the Roadmap is all about choice about where people live and with whom, where they work and what they want to do in community all with the UNCRPD being part of how the province moves forward. This has been a long time coming in Nova Scotia.

By meeting with and connecting with families throughout the province we were able to make sure their voices

were heard. Parents were brought together in thirteen communities in Nova Scotia. The value of parents connecting with one another is invaluable.

When asked, “Why do you think that bringing parents together is important?” One parent responded... “It’s very important. I remember being a young mom with a child with a disability. I felt very alone. It’s important because it is support. We learn from one another, as friends – our children learned and so did we. We’re stronger when we unite and we can advocate together. You don’t feel so alone because you have somebody to talk to about what you’re going through as a parent.”

Another parent responded “I think it is important because parents really don’t know what is available to them. One parent might be looking for something that another parent might have already experienced. It is a definite positive.”

Parents have, in many communities, expressed a desire to continue the conversations that began at these meetings. They were all very appreciative of being able to come together and hear messages of hope and see for themselves that change has occurred and that with the new “Roadmap” that more has to be done in order for their

family member to have choices in the types of independent living options. This type of collaborative approach can only lead to strengthening families in Nova Scotia. As a result of these meetings groups of parents are meeting on a regular basis in Cape Breton and Yarmouth.



## 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.

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

*"I recommend everyone possible to attend. This type of workshop is life changing in a most positive way."* Workshop Participant, Maple Ridge, BC



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