coming together

...to create change

A National Family Leadership newsletter

Volume 8, Issue 2 December 2015

inside

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.

50 years
Canadian Association for Community Living

Diversity includes.

Message from Barb Horner, Chair

Chair, CACL National Family Agenda Task Force

I recently had the immense pleasure of attending the international conference "Claiming Full Citizenship—Self Determination-Personalization-Individualized Funding." All critical elements of everyday life, if our sons & daughters are to claim their right to live in community always. As a parent, it was overwhelming at times, to hear all of the great progress from other countries, including best practices within Canada, knowing the way services have declined in my own province of Nova Scotia. It is a wake-up call to me as a parent. I know my daughter will not have a future of full inclusion and citizenship if I do not take action now. I also know that a collective community, no matter where we live, is more powerful than one voice alone.

My daughter has enjoyed an incredible, inclusive lifestyle in her community thus far. I desperately want the same for her future—a future where she is living in community, interdependently on her own with the supports she requires to continue to be successful in her life now and always.

So, what did I learn? Within Canada, 24% of the aging population will be over 65 by 2030 which impacts all of us as the issue of disability & dementia follows us as we age, along with the looming legalization of assisted suicide. That there is extensive inequality throughout our country in how individuals with disabilities and their families are supported and there continues to be high unemployment.

Michael Bach talked about the reality of government cutbacks and the withdrawal of supports and services just as the legalization of assisted suicide is pending. What does this mean for our children's future? Perhaps a little disconcerting. So what needs to be done to revitalize families and communities? This is what I heard...that a Vision for a good life for our sons & daughters is often limited by lack of imagination & knowing what is possible. There needs to be a renewal and a focus on family values, vision, dreams, aspirations. And that families may require support in navigating and facilitating inclusion, including

Continued on page 8

Build upon your child's strengths

By Michelle Archer
Saskatchewan

L to R: James, Michelle, Connor, Joseph and Drew Archer.

I'd like to introduce you to our busy family. We are the Archer's and are a family of five. My husband Drew and I have been married for 15 years. Our oldest son is Connor, he is 12 and has PDD NOS—a form of Autism. We also have fraternal twin boys Joseph and James and they are 10 years old.

Connor is vey active in a number of community activities – he is involved in a non-adapted Show Choir program with his peers at Class Act studios in Regina, and in several Special Olympics programs including peewee bowling, curling, athletics, bocce, and golf. He has recently started participating in a church youth group.

We became involved in the Special Olympics pee wee bowling program when he was 5. We needed opportunities to get him connected with his peers and bowling was a great fit. Recently he has expressed an interest in other Special Olympics programs so he has joined bocce, golf, curling and athletics.

Connor loves to sing and is very musical. To build on that strength and interest we enrolled him in a learn to sing program at age 9. He then transitioned to a musical theater program that included dance. Since the dance routine aspects of musical theater were becoming increasingly difficult for him, he then moved over to a show choir program which has no dance component—singing is the focus. This has worked out great for Connor.

Along the way, the biggest challenge were others understanding his capabilities and also a lack of understanding (or unwilling to learn) of his disability—his strengths and challenges. When there were challenges it was often because people would assume that he was doing things on purpose when in fact he couldn't control it. For example, Connor will often 'stim' in front of mirrors and blurt out things....these are behaviors that he works hard to control but they do make some people uneasy unless you know Connor. Yet despite his challenges.... at the end of it

all... he can sing! He is a great singer!

There have been some bumps along the way. Once, he was asked to discontinue a program — not because he couldn't do what was required but because the teacher was frustrated that he couldn't act like the other children. One has to wonder who has greater challenges... Connor or the teacher?

In helping us address situations like this, the support of other families has been essential. In addition, the staff and advocates of Saskatchewan Association for Community Living (SACL) are always there to listen and offer support and advice. I am connected to over 200 families through a Facebook group that I administer called the Saskatchewan Parents of Children with Autism Spectrum Disorders. Social media groups are a wealth of information and support for families.

School has been challenging for Connor (and for us). He does not have school friends and does not socialize with any of his schoolmates outside the classroom. He has not been invited to a schoolmate's birthday party in the entire 5+ years he has been at his current school. This is incredibly frustrating for me as his mom! We haven't been able to overcome that obstacle despite several "What is autism" presentations in his class, to his school peer group. You can show people why reality is what it is with autism but you can't force acceptance. So the recreational and social activities outside of school are my son's social network and provide him a place to be who he is and to form positive relationships with others. We believe these activities and the relationships he will form will be critical to his long term and full inclusion within community.

Just like with any child, I would recommend to other families that you start to enroll your children in programs that they are interested in—build upon your child's strengths! Try out programs offered by Special Olympics or a local arts or recreation group. Inform the leaders if you feel that it's necessary. Sometimes it is necessary to disclose the nature of the disability and sometimes telling the group leaders about the disability creates a perception of your child that doesn't allow your child to really show who he can be. Only you know what's best. I've learned that sometimes it's not worthwhile to disclose and it was the wrong decision, but I learn from my mistakes! Now I am more cautious about how much I share and to whom about my son's disability when starting a new program because

Connor's 11th birthday, celebrated at Magic Kingdom and Walt Disney World.

I don't want any limitations placed on him.

So my message here is that our children with different abilities can achieve and succeed despite any roadblocks! It takes a lot of hard work on your part, and a lot of advocating and educating others on the ability of your child. It takes thick skin for those times when the battle is tough. But every battle scar is worth it when you see the smile on the face of your child when they succeed, when they are thriving in a group and when you see that they are becoming a part of the greater community. My advice to you is to stay strong, reach out to other parents and organizations for support and know that you are having a huge impact not only on your child, but on the community you live in. Inclusion benefits us all!

Diversity includes.

Living in community is without boundaries

By Carole Chaisson
Prince Edward Island

As the newly elected VP of PEIACL, I am truly excited to participate in moving our Island towards a place where living in community is without boundaries to those with intellectual disabilities. After serving 30 years with the Canadian Military, in my retirement my desire to stay active in community in a meaningful way led me to, work with my brother Gordon to develop a life where he would live in a community and actively participate.

Gordon was born in 1966 an era that has stuck with him. His passions are music and cooking. He enjoys most gendres of music with a bias for 60s rock. The passion for cooking is in his blood, as both his father and sister were chefs in the Navy.

Born in a family of modest means and limited education, coupled with a diagnosis of Epilepsy and mental (R word) by the age of two was the beginning of many struggles for the entire family. This stigma left our parents with many concerns and unanswered questions about Gordon's future.

School at five years old was not a given for Gordon as with other children. Mom did not think that she could register Gordon for school, given his disability. A family friend told her that she could not simply keep him home and that he had to go to school. Our father was on deployment with the Navy at this time and mother waited for his return to discuss the situation further. Together they began the process of registering Gordon in a school for children with mental (R word) disabilities. For Gordon it was a terrible experience and after two years in this educational facility, our parents went to work to have him registered in a public school in a "special class". Gordon continued in special education classes to completion of High School, graduating in 1984.

Following High School, and for the next 20 years, the opportunities to develop life skills and experiences were limited to what family and friends were able to offer. There just seemed to be nothing for him that our parents were made aware of or were comfortable with, given his early education experience. Gordon mainly stayed home with family. In the mid 90s I was able to offer him the "trip of a lifetime", he accompanied my children and I to Disney in Florida. Shortly thereafter our father passed away suddenly and a huge void was left in Gordon's life.

Gordon became the "man of the house" as he continued to live with mom. In 2004, mom and Gordon packed their belongings and moved to Prince Edward Island. During the process of registering him for financial assistance, we were made aware of Community Inclusions agency. The staff came to my mother's home for all the meetings and the outcome was that Gordon was employed on a "part time" basis for three days a week at the Sandwich Factory in Bloomfield. He even learned to make a resume and develop interview skills to the point that he was hired on his own merits. He continued this employment until March 2007, when mom's health issues required them to move back to Nova Scotia to reside with my husband and I. Subsequently, both of us were transferred to Ontario and mom and Gordon continued to reside with us. During our time in Ontario we were able to show Gordon many attractions, Niagara Falls, Toronto Zoo, Marineland, and of course Canada's Wonderland where

Continued on page 8

Tristen's Story

As told by Lisa and Tristen

Ontario

When Tristen was born everything seemed to be progressing normally and then slowly he began to disappear into his own world. We received the diagnosis that that Tristen had autism when he was around 18 months old and we were told that he would never talk, that he would have no emotional attachment to people other than to use them for his own for fulfilment, and that he would be institutionalized by the age of 13.

Tristen was silent for many years.

He had many meltdowns which included flapping and moaning and he didn't make direct eye contact.

We were living in Bracebridge at the time and Community Living South Muskoka was involved right from the start. They helped us get crucial resources in place.

When Tristen was four years old we moved to Huntsville and became involved with Community Living Huntsville. Tristen is now 19, so we have been receiving support for 15 years.

Tristen was the first child in Muskoka to start intensive behavioral intervention therapy known as IBI. He really paved the learning path for many people to follow. It took years of hard work and commitment and then Tristen broke his silence at age 7.

I wouldn't be able to do all of this without Community Living Huntsville. It takes a whole community to raise a child. Community Living Huntsville assists me with piles of overwhelming paperwork that needs to be done on an annual basis for the government.

As a parent I did a lot of fighting on Tristen's behalf and would come in with guns a blazing. I wasn't going to take no for an answer. Community Living staff listened to our concerns and ideas. They did the finessing to soften and refine our approach.

Grade 8 was a very difficult year. There was nothing inclusive about the end of that graduating year for Tristen. The support we received through Community Living Huntsville helped Tristen with the transition into high school. Community Living Huntsville advocates on Tristen's behalf to make sure supports are in place and that his voice is heard. High school has been a blessing for Tristen. There is absolutely 100% acceptance and belonging.

Community Living Huntsville is currently assisting us with the transition into adult services.

Tristen is on a waitlist to receive supports and is waiting for funding for one-to-one supports which he requires. The future after high school is a little uncertain right now.

Tristen enjoys computers, nature, swimming, fishing, canoeing, animals, books, movies, and is a faithful patron of the library. Tristen especially loves art and is an exceptionally gifted artist. He has had a few art shows in Muskoka and has been featured in Arts and Entertainment of What's Up newspaper this summer. We felt over whelmed with pride and cried tears of joy watching Tristen, the artist, working his art shows.

The ultimate goal is to be able to afford to make a living from his artwork one day and the vision is to develop a website to sell his work globally. Tristen says that he wants to be a famous artist.

There is an art critic in the Toronto area who believes in

Continued on page 8

Diversity includes.

Active Youth

By Sue Horne
Newfoundland

Hi ! My name is Suzanne Horne and I am the proud mother of three children. Along with a beautiful daughter who is 26 years old I have 21-year-old twin boys, Daniel and David. Daniel and David were born with Down syndrome in St. John's at the Grace Hospital back in 1993.

At that time, I wasn't sure what their future looked like, but I knew that they would be surrounded by love and encouragement from family and friends. As we navigated our way through Janeway appointments and then primary/elementary school years I began to allow myself to think in advance about what types of lives they would lead as teens and then young adults.

Our first exposure to organized activities outside of our local Down Syndrome group was the Mount Pearl chapter of Special Olympics which has blossomed into a wonderful fulfilling way of life for both boys.

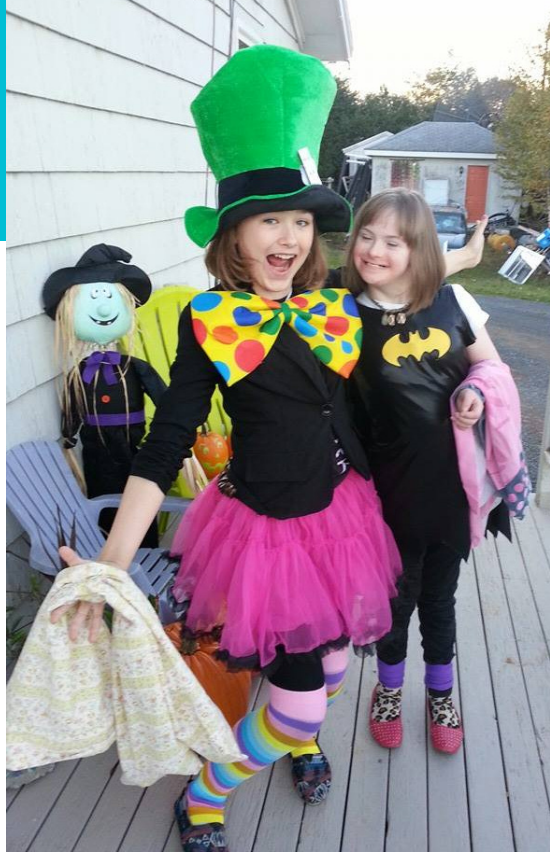
Approximately five years ago, we were advised of a pilot project entitled "Active Youth" that the City of St. John's Recreation and Parks Department were hoping to commence offering. They were looking for 10 participants with mild to moderate developmental disabilities to participate in recreation and leisure activities at various locations around the city. Our family immediately signed up and we have participated in this program for five wonderful years. The program has allowed my boys to develop new friendships, increase their self-esteem in a friendly, relaxed atmosphere. Their activities have included indoor sports, exercise classes, social activities, t-ball, snowshoeing , skiing and campfires etc.

This program is part of the City of St. John's Recreation programs and has offered wonderful exposure to my two boys along with 8 other young males and females ranging in age from 15 to 21 years of age. The caring, nurturing environment offered by the City's counsellors has only increased the effectiveness of this program. Every week, my boys are greeted with enthusiasm and genuine interest by their counsellors and are made to instantly feel welcomed and included in a very typical recreation environment. We went through an initial application/interview process to ensure that the program would be a good fit for our children. They were asked a series of questions about their likes/dislikes and the type of programming that would interest them. Since that day, we haven't looked back! Thank you to the City for identifying the need for a program like "Active Youth".

Parents should and must take the time to explore opportunities to have their children enrolled in programs that will help them grow and flourish. Our communities are there to help us achieve our goals.

Helping create a life for herself

By Martha MacLean
Prince Edward Island



Caption xxx

One of the first things I worried about, as I lay in hospital, recovering from an emergency Caesarean section, was:

HOW WOULD MY DAUGHTER BE TREATED?

You may think that I was putting the cart before the horse. After all, my daughter, Margaret, was less than 24 hours old, and may very well be flown to Halifax, NS from PEI due to possibly unstable congenital heart defects. Still, there it was, staring me in the face. My daughter was different. She was born with Down syndrome. I knew two things for sure. I loved her unconditionally. I was committed to helping her create a life for herself.

I needn't have worried. From an early age, Marg made friends easily. She was non-verbal, but never had a problem getting her point across. She was enrolled at a regular daycare center from 2 years old and is still friends with many of those same classmates today.

I paid special attention to whom she seemed to gravitate towards and kept lines of communication open between her caregivers, her pals, and myself. Frequent and constant communication ensured I knew who her friends were. When she was young, I set up "play-dates" for her. Now that she is older (grade 8), and uses an iPad, she can let me know who she would like me to call on her behalf.

When it became apparent that Marg would always need some kind of supervision, I helped her cultivate her friendships so that when the time came that the social divide between her and her peers started to widen, most of her friends have moved into a guardian role yet they still hang out as peers. For example, Marg comes home on the bus after school most days with a peer her own age. These peers are responsible yet respectful of Marg and truly enjoy being with her.

Don't get me wrong. These peers have a lot of responsibility on their shoulders when they come home with her and are accountable for her safety and well-being. Margaret's funding through the province of PEI ensures that I am able to put in a regular workday while Marg is hanging with a friend and is safe.

Am I paying for her to have friends? No. On several occasions, these peers put in extra time and refuse compensation for it. It is obvious to me in the way they interact that they are friends first. Of course, there are still the parties and sleepovers to which she is invited and these are not guardianship situations. Her friends' parents like having her around too!

People tell me that we are so lucky to have such great people around Marg. Yes and no.

Yes, we are blessed to have such wonderful people around us, but it is not luck. It is a concerted effort to help Marg create a life of inclusion. Now that she is older, I am proud to say that a lot of it happens naturally.

Diversity includes.

Message From Barb Horner
Continued

developing a plan for the future.

That innovation is key! And families **cannot** wait for government to tell them what is available, rather families need to tell government what it is we want for our families and our children to live in communities as full citizens lifelong.

One presenter suggested that the Keys to Citizenship include simple concepts such as "Purpose, Relationships, Support, Funding, Home, Love, Life & Freedom" – goals we all might aspire to, to live a good life. Another presenter talked about Key Lessons learned—that we need to know & highlight best practices & achievements of inclusion, the importance of government & community partnerships and that we have to respect the evidence of what we know to be true – continuing to learn, evolve & innovate. As families we have much wisdom, experience, passion and the power to make the changes we need! I heard very loud and clear that CHANGE happens at the community, local level and that families have always led the ***charge for change*** in our country and that right now, Michael Kendrick said, that, "A STRONG ADVOCACY VOICE IS OUR ONLY SAFEGUARD" for our children's future.

The most heart-searing comment made at the closing Plenary, for me, (my wake- up call), was by a mother who said, "How important it was to me, when my son died at the age of 30 years old, knowing that he had a life."

Living in community is without boundaries
Continued

Gordon was able to ride the largest roller coaster in Canada, Bohemouth. This adventure came to a close when I decided to retire in 2010 and follow my husband's career back to Halifax. Following a one year stay in Halifax my husband also decided it was time to retire.

The retirement plan, move to Prince Edward Island and have mom return to her roots. In 2011 we executed that plan and moved to West Prince and into our present home. Armed with the knowledge of Community Inclusions and the Financial Assistance available, we immediately embarked on the process of registering Gordon for the available benefits. During this time we were introduced to a housing option in Alberton that Gordon was most excited to explore and which he now calls his own and he continues to build interpersonal relationships with people outside of his family.

This new lifestyle has allowed Gordon to flourish and he regularly attends dances, plays and concerts. He enjoys bowling and socializing with the people he meets at the bowling alley. He continues to love cooking for friends at his house. While his employment situation remains a work in progress we are exploring some options through the Ready Willing & Able initiative sponsored by CACL. Gordon has developed in many ways that we had not ever imagined.

Tristen's Story
Continued

Tristen's talent and she is currently buying his art. She feels that Tristen will become established and when he does, she can say that she has some of his original work.

Tristen hopes to find a mentor in the Huntsville area who could assist him with developing and growing his art business.

Tristen is making his voice heard more, his confidence is growing and he makes more eye contact when engaged in conversation. Life is peaceful. The Community Living Huntsville Support staff connected to says that "Tristen takes obstacles and turns them into opportunities".

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 or 416-661-9611 ext 227, or your Provincial/Territorial Association.

Diversity includes.