

# **Breaking the ICE Conference 2017 - Reflections**

Compiled by Roslyn Irvine

## **Submitted by Farrah**

As an AAC user I found the BTI conference very beneficial to me. I liked hearing and seeing the presentations and it made me feel that I am not alone; there are other individuals with similar situations.

I was especially impressed with the attendant care persons. They made me feel good and I could trust them with my needs during the conference.

## **Submitted by Maria and Elena Chukalovskaya**

The BTI conference made me feel a sense of belonging and I would highly recommend it to parents or other AAC users. You don't need to use a device. It could be any type of AAC.

There are some events in our lives that we consider extraordinary. The Breaking the Ice Conference on October 28-29, 2017, where my 11 year daughter Maria and I were invited by Communication and Writing Aids Services from Holland Bloorview Rehabilitation Hospital, was one of these events for both of us and we are grateful for this opportunity.

On October 28 we arrived at the conference room at Novotel a bit later, when registration had already finished. All of the participants had formed a big circle and listened to the rules for the discussion of the Town Hall Meeting questions. "People who don't use AAC are not allowed to speak unless they help a person whose communication requires that." This was the meaning of the first message received by my busy and confused brain while I was making Maria comfortable in her chair and adjusting the position of her communication device, trying not to distract other people around. Probably, because I was so busy and confused, this message hit its target exactly; without rational protection it was met by unrestrained ego and it was fun to hear it screaming: "Am I... Am I not allowed to talk?" It didn't take long to realize that as a guest from "another" world I was treated fairly. Since my daughter augments her speech using a personal computer with communication software and single switch scanning which requires significant time to type any message, I know very well why people with communication disorders may feel like they are "not allowed to talk" and be frustrated and uncomfortable while communicating to unprepared people; the people from "another" world to whom they addressed the restricting rule. It is an unpleasant moment for me when I have been unprepared and felt frustrated, but people who have gathered in the conference room feel much more than that every day of their lives, every time when they face "another" world.

Here, in the conference room they were among friends, among people who most of them knew for many years, so the discussion was very open. The questions were: What do you do to make a difference? Who do you know that has made a difference in your life or other people's lives? How do you pay it forward?, What would make your life better? I was impressed with how much these people were able to do to make life around them better and how deep and honest most of the answers were. Being at the conference for the first time and mostly surrounded by adults, but

fully consumed by the open and friendly atmosphere, my 11 year old Maria started to type her answer and read it to the audience: “People from Holland Bloorview Rehabilitation Hospital made Hummer switch for me, they programmed my computer. Ari Rivera, Jennifer Morin, Linda Buskin, Doctor Chau, Lesley Mumford, Fanny Hotze, my Mom. I can talk, try to help everyone. I like that people understand.” “Laurel helped me. She programmed my device. Laurel is my friend and we laugh together. She is a very special person to me. Everyone needs a Laurel”– said 10 year old Joseph later during his own presentation.

Many of the participants had this in common: the people who had helped them to find their voice and ability to communicate made a huge difference in their lives. Therapists and their loving families formed the list, but not only them. Their wise friends, people using AAC and who had passion and courage to become mentors to others also were treated with great gratitude and respect. Even those who had passed away were unseen but present in the room all the time.

People needed to talk, they were very well prepared to talk and they talked a lot. They needed to share their thoughts and worries, to talk about problems and solutions. They felt that it was necessary to tell about people who supported them, about their families, friends and pets. They were proud to tell about their accomplishments, they were silly when they told jokes, and they laughed a lot. Panel discussion about friendship and relationships and wonderful presentations by Zhade, Tien Hoang and Jessie Weber made me think about my own relationships with people around me. I have to be honest and admit to myself that I have never thought about some aspects of those relationships as deeply as the panelists did. People at the conference talked about the most serious and important things in human lives and this communication was bright and brilliant.

A lot of problems that people with communication disorders face in their lives were outlined at the conference.

The presentation by 10 year old Joseph Spahn-Vieira, supported by his family, gives a great example of how a child who uses a communication device from a very early age can be effective in communication. “My Vanguard is me” states Joseph, but he and his family are very worried, since his device is not being manufactured anymore. Joseph faces a problem created by the adults who don’t care and don’t take responsibility for what they do. Joseph probably is not alone and there are many people who use the device and get used to it, but as it has been discontinued, they struggle to find a substitution. For Joseph it is very difficult, since he can’t use another one as successfully as Vanguard: “Please bring my Vanguard back!” he stated.

Almost everything in life can become a problem for people who have different physical and communication abilities. According to Zhade, so many things are real barriers for people with communication disorders to build friendship relations: “Attitudes can be an issue. Accessibility is an issue. Transportation can be an issue. Washroom facilities can be an issue. Staff support can be an issue... ”. Misunderstanding, miscommunication, misjudgment – these are not the only huge blocks of the ice that people with communication disabilities face all the time.

Thanks to the committee who organized the conference, people who required assistance and support felt comfortable at the conference and many problems just didn’t arise or were solved

quickly. People from PACE Independent Living worked hard and made everything possible to provide excellent care to everyone who needed it. I can't not mention the delicious and "accessible" food and the dedicated work of the Novotel staff who provided the catering services and made this event very festive and pleasant for everyone.

In the evening, it was a real miracle and a great pleasure to everyone in the conference room to enjoy wonderful music performed by The Bliss i-Band, a Toronto group of 12 members that explore group music-making through the use of iPad-based virtual instruments.

It also would be great to dance after this long and busy day, but Maria chose something more important. Her friend was feeling unwell and she decided to pay him a visit to make his evening a little bit more pleasant. She was also very adamant in her decision to come to the conference the next day, so I had to adjust my plans.

The next morning the Time Capsule event was very interesting for the participants. Maria, as well as many other people, presented her letter to the future and put it into the time capsule with a photo of her and her new friend Liam, who was also at the conference.

The final event was the presentation of Barbara Collier, Executive Director of Communication Disabilities Access Canada, an organization promoting human rights, accessibility and inclusion for people with communication disabilities. Barbara finished the conference with her presentation about Communication Access Rights in Legislation. This information was new to me and also extremely important since as a mother of a child with a communication disability I have to advocate for my daughter a lot. So as to not do it only on my own, it is a great relief to realize that I can rely on the great resources and information provided by CDAC.

My daughter Maria was certainly inspired by the conference. Right after the event she typed: "It was awesome. People with communication disabilities. I learned something important but I don't know exactly." A few days later she wrote: "I agree...that people can accomplish a lot if they want to. For example, I was at the conference and saw many people who use communication devices or something like that. I use communication device too. It was not easy to learn how to use it first. I wanted. I was trying and I never gave up. Now I use it at school, at home and everywhere. I use it in Russia and other countries. I want to talk to people who need help and support and I do it".

Maria certainly learned something very important. I wish that her positive intensions do not get blocked by a wall of ice and that she finds her own way of how to make our world better. I know that she will be supported not only by her family, school and therapists, but also by the wonderful people she met at the conference.

I wish our society became mature, informed and educated enough to provide equal rights for communication to each and every one of its members no matter how different their communication abilities are. I wish people with communication disabilities never felt like they were restricted and not allowed to talk and that they never had to think about setting restricting rules at their conference even as a joke. At this conference, the two worlds of different

communication abilities eventually became one. One beautiful world of human communication. I wish I can help. I know I will try, we both will try, Maria and I, we will.

**Submitted by Casey Morrison**

Hi, my name is Casey Morrison from Collingwood and I am an AAC User. I am a client at Holland Bloorview in Toronto. I attended the ICE Conference in Toronto last month! I learned a lot there and saw old friends and make new friends! I remember Barbara's quote. "AAC Users have fallen between the cracks and we need to get together to talk about it." I really hope you will keep ICE Conferences going!!!