BC HANDS & VOICES

December 2009

BC Hands & Voices is a parent–driven, non–profit organization dedicated to supporting families with children who are D/deaf or hard of hearing.

We are a parent/ professional collaborative group that is unbiased towards communication modes and methods, believing that families will make the best choices for their child if they have access to good information and support.

Our goal is to support families in achieving successful outcomes for their children.

Parents Sharing Their Experiences

Another Successful Event by BC Hands & Voices

By Cathy Luther

On Friday, October 16th, BC Hands & Voices held its 3rd event, this time hosting a parent panel. The event was held at Provincial Services for the Deaf & Hard of Hearing, at the Victory Hill site in Burnaby. We would like to express our gratitude to them for allowing us to use their boardroom for our event.

The panel was made up of parents who are either or both on our BC H&V board or who are members of BC H&V and are parent guides from the Guide By Your Side Program. Participating on the panel were: Amy Ho, Bobbi Best, Terri Dauvin, Monique Preer & Chris Mallinson. Each of the parents on the panel hoped to share their experience and knowledge in raising a child with a hearing loss with the parents in the audience and to answer any questions that the audience might have.

14 parents and a family friend attended the evening and made up our audience. Not a bad turn out for such a miserable night…rain, rain, rain.

The evening proved to be a success, however, there was just not enough time, as is usually the case.

Upon arriving and settling in, we began by introducing the Hands & Voices board parents and parents on the panel.

Moderated questions covered the topics:

1. What challenges the families faced and how they worked through them
2. How they dealt with questions or lack of questions from relatives and friends
3. How immediate and extended family members were affected by their child’s hearing loss
4. Their feelings on the roles of Dads vs. Moms

Thoughts & experiences shared by the parent panel:

Dealing with challenges

It was difficult to find services in outreach communities. However, supports are available if one is willing to do the work of looking, asking, and sometimes traveling to find them.

Being the main person to become educated about hearing loss and what to do to help his/her child. The parent is then considered the “expert” and feels the responsibility of making his/her child’s experience a success. One parent wished she had involved others (family & friends) in appointments and in the education process.

Being new to the country and not knowing what resources were available.

Having to choose a program for services and make decisions like “use sign language or an auditory/oral approach”. One parent felt she needed to make one choice versus the other, but later learned that they could change their approach as their child’s needs changed.

One child was born with many other challenges. When the parents learned that their son had a hearing loss, it was viewed by them as an issue that could be dealt with later, when their child was well enough to come home from the hospital.

Questions or lack of questions from others

Gave them the facts/information about their child’s hearing loss and hearing aids.

Shared with them some ways to communicate with their children.

One parent commented that, “I am always pleased when people ask me questions about my son’s hearing, as I feel that teaching the people in his life about his hearing loss will ultimately help him.”

Immediate & extended family

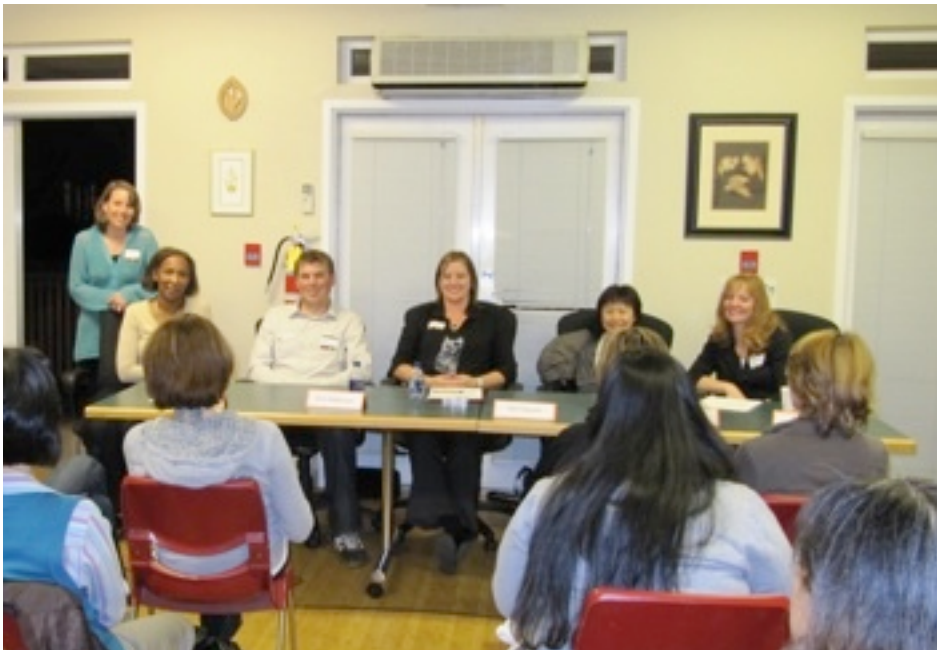
Extended family benefited a lot from having children with a hearing loss in the family. They were brought together in a way that might not have happened otherwise. They all learned a lot about tolerance and acceptance.

One son who is sandwiched between two deaf siblings finds it hard sometimes, so his parents do their best to find time to spend with him alone.

One parent talked about how her family all went through a grieving process, but was confident that they could handle the challenges, and that their deaf daughter could do as well as their hearing son. She also commented that there was a very strong bond between her older son and her daughter with a hearing loss, and they value each other’s ideas/views very highly. For example, when her daughter was in Grade 11, she wrote an award-winning contest essay about how her older brother helped her improve her reading skills by bribing her with her favorite candies to get her to read more advanced books when she was in elementary school. A few years later, her hearing son would write a university Psychology paper about how his deaf sister acquired the English language despite her deafness.

Roles of Dads vs. Moms

A Dad’s role is very important and just as important as a Mom’s role. Sometimes, husbands can come to meetings and doctor’s appointments, other times work prevents them from coming. One parent said that she is, “always careful, when I talk at these appointments to say ‘we’ because even though he is not there, it does not mean we have not discussed this at home (together



"Give your child the choice about providing information about his/her hearing loss to those involved"

as parents or as a family)," and this should be made clear to the children and others.

Mothers and fathers should share the same responsibility.

One couple attended almost all medical and school appointments together except for the weekly physiotherapy sessions for their daughter's first 2 years.

When advocating for their daughter, one husband often edited the letter that his wife wrote so as to add more emphasis to the request by making it more concise.

The only father on the panel talked about how he had attended all of his son's many surgeries, but felt terribly guilty when he had to miss one minor surgical procedure.

We all agreed that it is important that having both parents active and involved will lead to the greatest success for the child and the overall well-being of the family. It is crucial that everyone feels supported but this can look different in every family.

A parent in the audience wished to hear from the panelists about their deaf/hard of hearing children and the children's participation in group activities such as sports, clubs, etc.

Responses from the panel

"My daughter is involved in several different sports. She participates in dance classes, basketball, horseback riding and cross-country running. She likes to ride her bike and four-wheeler. She has joined other activities like piano and choir. We find it helpful to use the FM system when we are going for a family bike ride."

On self-advocacy: Give your child the choice about providing information about his/her hearing loss to those involved (coaches, instructors, leaders, and the other children). Do they want to talk about their hearing loss themselves or would they prefer their parents to give that information?

Ensure your children make people aware of their hearing loss when they are in situations where they cannot hear. For example, children do not wear their hearing equipment when swimming. Tell your child to inform the lifeguard, "I am deaf and can't hear you" when the lifeguard is talking to him or her.

Parents found it really helpful to be a parent helper or leader in their child's activities. One parent always went on field trips with her son, which was a great time for other parents to ask her questions about his ears and hearing aid. The questions came up naturally and she was able to help them better understand his needs. She recently was a trip chaperone, and even though her son is now a teenager, she was amazed at how many of his peers, other parents, and instructors asked her questions about his hearing.

One parent asked the swimming instructor to let the other children go first so that her son could watch the other children and know what to do, since he couldn't hear the instructions. She also talked to the instructor or coach ahead of time, with her son, to explain his needs. As the son grew older, he took this role upon himself.

From Families to Families

My Personal Challenges in Dealing with My Son's Hearing Loss

By Jenn Kipling

“Nothing is wrong with him. Why do you ask?”

My son Connor was diagnosed with a mild bilateral hearing loss at birth. At the time of diagnosis, I went through the typical grieving process but Connor having a hearing loss really didn’t affect me because I myself have a mild bilateral hearing loss and I’ve managed just fine. However, I didn’t anticipate the personal challenges I would face as a parent with a child that has a hearing loss.

My first challenge was my family — my husband and his parents in particular. They had this need to place “blame”, to find a reason for why Connor was inflicted with a hearing loss and that need of reason or blame fell onto me because I of course had a hearing loss myself. And I myself had already been down that road of placing fault onto myself but changed my tune quickly. My hearing loss was caused by a reaction to medication when I was a toddler and the testing showed no indication it is genetic. I feel that on the most part they have gotten over the “blame game”, but every now and then one remark or another will be made and I just cope by ignoring the comment and responding by pointing out something amazing about what Connor is doing or has done and what a great child he is.

My next personal challenge came after Connor was wearing his aids. I love his aids, which are cute baby blue ones that match just about everything that he wears. I was really good about having him wear them. I don’t wear aids myself, and I taught myself to cope without them. I really wanted to make an effort to make sure Connor would feel comfortable growing up with them and not feel embarrassed about wearing hearing aids the way I did when I was a kid. But it then became very evident to me by having the baby blue which stands out, that I would be asked questions about them or Connor. I was totally not prepared for these questions and found myself on the defensive at first. Some examples of these questions and responses are: “Oh what are those things?”, or “What wrong with him?” Or having people snap their fingers to see if he would respond. It really took a lot for me to react calmly so that Connor wouldn’t sense my tension or frustration when I responded, “They are hearing aids. My son has a hearing loss”, or “Nothing is wrong with him. Why do you ask?” or “Do you usually respond when people snap their fingers at you?” (That was not one of my finer moments.) Learning to react calmly has been a great challenge for me and on the whole I do manage to be calm.

My final personal challenges have been in the last year, which has been an amazing year of development. I have been constantly questioned about the fact that Connor even has a hearing loss at all. And sometimes I would even question it myself. So the struggle has been to remind myself that, yes, he has a hearing loss and learning how to explain it to others so that they will understand. “He hears things more quietly than you and will miss sounds and words when he’s in noisy situations” — these I find are the easiest to use.

However, even though I know and remind myself on a regular basis, I have been not so diligent about keeping his aids on. This is mainly due to the fact that he functions so well without them, and he likes to take lots of breaks

From Families to Families

My Daughter Swallowed a Battery!

By Bobbi Best

I would like to share a story that as a family we laugh about now, but at the time it did not seem that funny.

My daughter was about 19 months old and had had her hearing aids for about a month. She was getting used to them and was starting to leave them in and not pull them out constantly. I was cooking dinner and she was sitting on the floor in the living room playing with toys. I was busy in the kitchen and when I looked to see what she was doing, because she was being very quiet, I saw that she had the hearing aid close to her mouth and then I realized she had something in her mouth.

I knew as soon as I got to her and saw the hearing aid in her hand without the battery what she had just swallowed. I immediately phoned the nurse help line to find out what I should do. They told me to go straight to the emergency room. Since we were new to the area, I had to find directions to the nearest hospital, and then off we went.

I had my daughter and my two sons with me, as my husband was working at the time. The nurses took us to a room right away, and we did not have to wait long before the doctor came in. He said it was not likely a problem as long as the battery had traveled through the stomach quickly. The doctor said if the battery was in the stomach too long, the acid in the stomach could start to break down the battery and cause a serious reaction in her stomach. So she was sent for an x-ray; luckily for us the battery was in the intestines and was on its way out. So with a sigh of relief we went home.

The next day, the battery was revealed in her diaper. No I did not save it, however, the thought briefly crossed my mind! My daughter is six now and she likes to hear me tell the story; she thinks it is funny and a little gross!! I know that most hearing

Early Drawing Gives Children an Advantage in Gaining Literacy

By Bob Steele

Some 20 years ago a group of parents, teachers and academics got together to foster mental development and literacy in preschool children and beyond. They called themselves the Drawing Network. Language in the broadest sense would be the key and spontaneous drawing the special emphasis. Children begin to draw about the same time they first use spoken words, typically in the second year of life. Nature apparently meant this to be used as a language medium. A fairly consistent unfolding takes place, but only when parents and teachers nurture it in a daily routine. Drawing begins with random scribbling, becomes crude representations and, by age four and with daily practice, emerges as a medium of expression so rich and detailed, so useful in expressing a subtle and complex content, that the definition of language is richly satisfied.

The Drawing Network defines language as articulating, expressing and communicating perceptions, thoughts and feelings. Drawing not only fulfils this definition but has one enormous advantage for the child who must use language to face the world intelligently and with feeling: unlike literacy, drawing has no code and children use it with complete spontaneity.

To end the relative neglect of drawing as a language medium, the Drawing Network suggests the “daily draw” in homes with children. Here is how it works.

- Simple materials are provided – recycled computer paper, cheap drawing pads, ballpoints pens and safe-to-use fine-tipped felts. The literacy connection begins with a conversation between parent and child about theme. Ideas are exchanged. Shut-eye visualization and guided imagery may be helpful. A story is told, a poem read, a notable event recalled, a household routine highlighted. The adult has no further responsibility, only motivation; no “showing how”, no “how-to-draw” formulas.

- Words also come into play during the drawing performance in the form of a silent monologue. Vocabulary is stimulated by drawing “things” in detail; the natural laws of syntax are exercised by echoing the events of the drawing with a silent running commentary. When words seem appropriate they are added to the drawing thus making the transition to writing and reading.

- The parent returns when the drawing is finished and the literacy connection reconvenes with a post-drawing discussion.

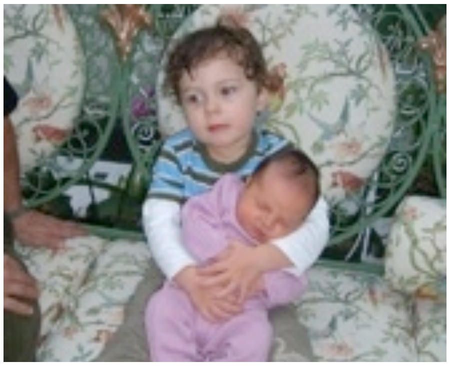
The child who is encouraged to draw has a tremendous advantage over the one who either draws fitfully or not at all. There are developmental gains that include increased perceptual acuity, intellectual growth, emotional, health, a happier learning environment, bonding with parents and other adults, learning to face the natural and human environment with empathy. The unexpected advantage, however, is the easier acquisition of all forms of literacy.

Bob Steele is an associate professor (emeritus) at the University of British Columbia and is with the Drawing Network. It is online at:

drawnet.duetsoftware.net

The article first appeared in the Vancouver Sun, March 3, 2009. Reprinted with permission. Professor Steele has kindly agreed to offer his assistance to BC Hands & Voices and individual parents via email exchanges, no fee required. He can be reached at drawnet@shaw.ca

Congratulations!



Jenn Kipling

Congratulations to Jenn, our Treasurer! A beautiful baby girl Hannah was born last month to the Kipling's.

Monique Guterres

Monique is the proud winner of the Dr. Charles A. Laszlo Scholarship awarded by the Canadian Hard of Hearing Association (CHHA) this year.

Monique was born hard of hearing. She has been using a cochlear implant for 7 years. She is taking the M.A. program in criminology at Simon Fraser University. Her goal is to study environmental criminology. Right now, she is also doing a part time job with the Institute for Canadian Urban Research Studies. In addition to all these, she is the BC Youth Director of the CHHA – Young Adults Network.

It is inspiring to see what she wrote in her application for the scholarship, as printed in the 2009 October issue of the CHHA Listen magazine: "Success isn't measured by how many decibels you can hear, but it is what you do with the decibels that you have."

Rosalind Ho

Rosalind is the proud winner of the first BC Cochlear Implant Community Award this year. This award for post-secondary students was set up thanks to the generosity of Dr. Sipke Pijl and Mrs. Lois Pijl.

Rosalind was born with a severe to profound hearing loss. She has been using a cochlear implant for the last 17 years. She is currently studying at the University of British Columbia towards a major in English Literature and a minor in Political Science. Apart from her heavy involvement with a UBC student newspaper and the American Sign Language Club on campus, she also holds 2 part-time jobs. Rosalind's goal is to do advocacy work for people with disabilities,

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