

BRIDGES-OVER-BARRIERS



A bridge lets you reach across a barrier to a place where you couldn't go before. But Bridges-Over-Barriers isn't something that other people have built for you, like the keyboard that you use; it isn't something you can buy in a store, and in fact, it isn't a 'thing' at all. You are the bridge, you have built it, and it can't exist without you. Like a bridge made of metal or wood or stone, each part plays an important role in the structure; it depends on each of its parts for its strength. Perhaps the miniature bridge will remind us of the strong structure that a small group of determined people, working together, can build. It stands on the strong foundations of families and other supporters, but, like the metal struts and the rivets that work together, it's the Bridges people themselves who are the structure that reaches across the communication barrier.

Our friend Andrew Foster is giving us a model truss bridge as a mascot of our Bridges group. He also designed this logo and composed these words about what our group means.

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BRIDGES AS OUR SUPPORT GROUP

Bridges is a community of communicators, and also a support group for its members. We care about one another. Using Supported Typing, we share our struggles and the sad experiences of our lives. When one of us feels distress and loss, the rest of us imagine and share the hurt and sadness. Sometimes we talk together with S-T in our gatherings about strategies that could help when one of us is going through a hard time. Sometimes we can only feel for our friend and send our love without words.

During the six years that we have been meeting, Bridges members have experienced change, distress and loss. Tim Marmura and his mother Betty, in particular, lost first Tim's grandfather in April 2007, and then Tim's father in September 2009, soon after the Marmuras had moved to Antigonish, Nova Scotia.

We know how very close Tim and his parents were to one another and that this loss is overwhelming. It's hard to know how to help. I, Andrew, think of these words that Betty offered me, when my grandfather died in December 2007: "He has given you his own brave spirit, to guide you on your life's journey."

Betty suggested that people wishing to give in memory of her father and Mike might make donations to Bridges. Memorial gifts for Charles Carscallen, Michael Marmura and John Bloomfield are being used towards the costs of the Bridges video and IT infrastructure system to help our gatherings work more smoothly and also help us to keep in touch when we cannot travel to meet in person.

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WHAT WE SAID AT RECENT BRIDGES GATHERINGS

(26 September and 31 October 2009)

In several gatherings in 2009, we explored our senses, including our perceptions that are affected by the symptoms of Autism. We tried out and discussed how we experience our basic senses of smell, taste, vision, hearing and touch. We found that we can differ quite a lot in our likes and dislikes of specific things we taste or smell. We tend to be most hypersensitive to sound and touch. Some of us experience a blending of senses or synaesthesia. Seeing something may also bring a strong sensation of odour or taste. Or when we hear a sound or word or name, we may see a particular colour. This may be more common among people with symptoms of Autism. It may explain why some of us are artists or express ourselves in poetic metaphors.

Perhaps the interaction of our senses explains why some of us have problems with two other senses-- the vestibular (balance) and proprioceptive (sense of our body in relation to surrounding objects, people and spaces).

Some discussion of our senses has been reported in a previous Bridges bulletin, including our multisensory experience of nature (#8, September 2009). Here are some thoughts about an experience of sound, rhythm and music, as well as about our total sense of security and well-being.

Deborah Seabrook, Music Therapist and with Wilfrid Laurier University, explained that she would play four pieces of music, with time for people to comment on how each piece made us feel. She suggested we might close our eyes, and take deep breaths to help us concentrate.

“How do I hear and feel sounds, rhythm and music--in my heart and emotions?” when hearing a piece of Bach music.

KM: I like that kind of music. I felt at peace and I enjoyed listening. I think we should listen to more music.

SL: It makes my heart feel warm. Like a Merry Christmas sensation.

KR: The music made me feel nice inside. It takes over my sense of sight. It is an awesome thing that takes me to a happy place.

AB: I hear the music in my head and then it makes me feel like swaying. That means pleasure.

JMD: [who can only hear piano music, because of his hearing loss] I hear the music and feel good.

KV: I felt that music in my soul and whole self. It was beautiful and lovely and tranquil. It reminds me of my childhood and my mother's studio.

MM: Nice to listen while I think. Emotion is wholes and cares big and small.

With a second piece, we considered: **“What do I feel listening to different kinds of music?”**

KM: I feel happy like I want to dance. I like the happy high notes. I can see myself jumping and clapping to the music.

SL: It made me feel like dancing. I can't sit still when the beat gets fast. It makes me want to move.

KR: Felt better than the last piece.

AB: I felt uplifted and my blood pressure went down. I know that because I feel myself doing it. My feeling is we should use Deb instead of drugs.

JMD: Good music, happy, feel joy.

KV: That music was too loud and discordant, but it had a lively rhythm. I wanted to keep time with my body. I also wanted to cover my ears.

AB: I also want to cover my ears when music is loud.

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KR: It depends on what you like. I prefer a loud thumping noise but the soft sounds relax me. Maybe you want to be relaxed now, rather than revived. It is good either way. We are all different. It makes us unique, just like the music.

Listening to the third piece that had no consistent rhythm, we considered the question **“How do sounds, rhythm and music affect our ability to express ourselves?”**

KM: I did not like that music. I felt I wanted to block my ears. I don't like slow music and I don't like the odd sounds she made on the piano.

SL: I felt like something was needed to complete it. Waiting made me feel a bit worried. I like being able to expect the song. It is calm, but too much of wait.

KR: Nice but too slow. I feel tired. I think we are all so different and that is very interesting. We are all so unique.

AB: I really related to that. I like piano. Electric guitars or drums--it bothers me. This one would be good to go to sleep with. Very mellow. Quiet flowing music helps unlock my thoughts.

JMD: Sad music helps me to think about grandma.

KV: I liked that music. It was like a relaxing walk along a nature trail with frequent pauses to read the signs or listen to the sounds.

MM: Like that one, very slowly. Music is nice in all shapes and sizes.

SL: I liked to listen to the music. Neat to hear how different everyone's opinion is of it. Kind of funny I think.

Deb then played a piece she has composed.

JMD: Happy music makes me feel good.

KV: That was interesting and sometimes unsettling. It was descriptive, sort of like a long conversation with lots of commentary and questioning.

MM: I was trying to right myself [music helped].

KM: I liked that music. It is happy and dancing music. I liked the notes skipping fast in the music. I think I like listening to happy and fast music, not slow and quiet music.

SL: That was beautiful, and makes me have that Christmas feeling again. It is an event waiting to happen and when it does, it is a welcoming feeling like being here with my new friends. It is a good and peaceful thing. I like it.

KR: Good but slow. I think this one was very beautiful. It trickled like running water. It is a feeling of water and trickling brooks and like the waves at the beach when I was at Mom and Dad's at the lake. It is a lovely feeling of contentedness, if that makes sense to you. I can't explain how nice it is. Just water is a good thing.

KV: I agree that it sometimes sounded like rippling streams and bubbling fountains.

AB: This one would be good to have as background for my typing. Thank you very much, Deb. Please tell us what part of the brain responds to music.

Deb replied that music makes us feel more engaged because it involves both hemispheres of the brain, as opposed to language which uses just the left hemisphere.

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WHAT WE SAID AT RECENT BRIDGES GATHERINGS

WHAT DO I NEED TO FEEL A SENSE OF SECURITY?

JMD: I need a great family and good friends.

Kind people help me to have a good life.

KR: I feel most secure with my Mom. I love her so much. She always loves me even if I am a jerk. The feeling that Mom gives me makes me know that I am good and respected by her. I like to be with people who know me best, not with strangers. They fear me so I feel a bit insecure. Probably like they do. I like the feeling of a safe home, like I have. The thing about family is that they love you. No matter what, they always love you.

SL: I feel secure when my parents are with me. I love my family. They have always been supportive of me, almost too much because I have always had them.

KM: I need people who need and love me and believe I can do things. My family gives me security by being with me all the time. My family tried to help me do interesting things and they have meetings with people who help me have a good life. I feel secure when people accept me the way I am. I need people to think I am smart and I can do things. I feel secure at the farm because I can do the work and I am a good worker and David likes my company.

AB: I need to be with the people I love and who know me. I think knowing me includes knowing what I need such as good diet, S-T, time to get going, and my dogs. My parents know me, listen to me, and work with me to make my life fit me.

MM: Happy to have my family cheer and teach.

KV: Family accepts you unconditionally. They love you when your behaviour is odd and they have faith in your capabilities and intelligence.

WHAT DOES SECURITY MEAN? DIFFERENT THINGS TO DIFFERENT PEOPLE?

SL: It is feeling safe and at home with people, not with strangers. I think secure might mean money to some people. I think that sometimes gets away from the real meaning and people get lost... I need money but people are more important to me and I know my parents will make me secure if I have them in my life.

JMD: Understanding what is going to happen and really being Dad's partner.

KR: Having the people I need in my life, not the things. It's nice to have things, but people are the most best thing to feel part of a secure life.

AB: It means being safe with no worries. It means being sure I am OK, not left in uncertainty. There are so many kinds of security, too many to mention.

HOW CAN THOSE QUALITIES BE STRENGTHENED IN OUR LIVES?

KV: Other people need to accept me better. I need to find ways of interacting with them. Then they will respond accordingly. We need to be able to communicate with others spontaneously. We need to entertain ourselves and, as far as I can tell, look after some of our own care.

JMD: Help me to make friends. Treat me like a man—everyone!

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WHAT WE SAID AT RECENT BRIDGES GATHERINGS

MM: You will tell them to respect me. Try to feel my autism. Respect every day.

AB: I need others to learn from my parents. I cannot depend on them alone. I need to tell people what I need. By typing and inviting others to listen. I need others to learn from me by spending time with me and at Bridges. I think exposing others to our ideas will help me get known and feel more secure. I want to practice S-Ting with less support.

KR: I need to trust other people to be helpers like my parents, but I need to know people well to let them in. Our lives are not in our control, so I need a plan.

SL: Feeling loved by family is because they know me. If people get close to me, they will know me and love me too. That helps me to be a better person in whole which will help me improve my life. I want all people to love me. Just get to know me. I can let people into my life so they get to know me. If I put it out there then maybe they'll enter my world.

KM: I need help to go out in the community because I can't speak words. I need people to S-T with me and be my friend. I need more people to understand me and take me out to work at the farm every day.

HOW DOES COMMUNICATION FIGURE IN MY SENSE OF SECURITY?

SL: I don't have enough communication. I get insecure when I can't communicate with people. I don't like to be forced to talk if I am not ready. I get scared if I try too hard but sometimes it is too

much like talking. I want to S-T more but I am lazy and don't do it enough.

KR: Directly. It is really important but if I'm not able to S-T, I get mad and stuff happens that is not my fault (all of it). I think this group helps me feel secure to talk with others who feel the same way. I feel secure most when I can talk about things I want. To feel security more and more maybe this will be a step.

JMD: Having DynaWrite helps me feel secure. It helps very much.

AB: It is big big big. The ways I communicate are numerous, by S-T, sign, moving. If people are not in tune with my communication, I am not secure. I want people to think I have something to say worth hearing, not just to talk and be heard. That makes me feel secure. I'm insecure if people don't believe I can communicate my own thoughts. People need to continue to talk to me about everything on an ongoing basis, not just to get an answer. I like people to talk to me, not just to people with me. I want to know the details, so always share with me. I don't like it when people talk away from me. Yes I need so much that people realize that communication is the most important thing in my feeling secure. I need those who are important to me to communicate with me. When I have something to say, I have to wait to say it. And I need to know that people have got what I have said. So many people don't communicate back to me. I think communication among all people in my life is important.

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WHAT WE SAID AT RECENT BRIDGES GATHERINGS

HOW COULD BRIDGES HELP US ALWAYS TO HAVE A VOICE?

KM: Bridges can help a lot with the movie we are making to show people that we can talk, that we are smart and can think for ourselves. I think more people should come to Bridges to see us talk to each other on our machines. Talking people should come and learn that we can talk with our machines. We know what is going on and understand what people are saying. They need to hear our voice.

MM: Be here. Strong, happy friends dream together. Thanks to everyone. Always here for me.

KV: Sharing ideas is helpful. Also it's reassuring to know that other autistics feel like me.

JMD: Good to really share feelings with the group.

AB: I think we should support each other with learning together in workshops and courses, and spreading the word like a book.

SL: I love telling you these thoughts. This is a good feeling. I wonder how I can do more of this. I think I want to be a stronger communicator.

AB: I would like to know how other people deal with the feelings we have talked about. I use S-T to express myself, but what do others do if they don't S-T? That would be so frustrating if you can't. In an ideal world, everyone would live with S-T assistants for ever at all times.

KR: I think I feel respect here but not everywhere. I like being part of this group. Thank you for sharing your lives with me. This group has given me an opportunity to be a member of something.

It gives me a role and that feels good. I love having people around me who understand me and like me. That would be nice, to have this feeling all the time.

SL: I want to know how to deal with feeling alone. When people don't include me.

JMD: It is hard to be deaf, so hard. I feel alone and sad.

KR: I feel that way a lot too, Sara. I don't know if I will ever feel totally included unless everyone communicates with me in some way. Like people talking when I am not in the room; I can still hear them and that makes me angry and then I feel alone, like no one is listening to me. Just remind people to talk to you and then put an effort into talking. However you can try and try; I have to. I get what you mean... Hang in there.... I feel the same. Even when I hear, I feel alone.

SL: It is a big help, that I can talk openly about this here. Then I feel more proud of who I am. That has been part of being a group like being on a team. I like you all so much. It makes you feel you belong, like a team. I belong!

AB: I think it is true this kind of activity helps us connect with others who don't do S-T with us. I think our gathering is calm, and I hope people will learn from us. Our Bridges movie should help too. I get to be included in everything because I help plan my life. A circle should help you be sure to be included. It is sad if you are not. But being alone at times can be good for us too.

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ANDREW THE RUNNER, MAN OF PEACE

I am a man of 41 who recently discovered the joys of running. I live with severe symptoms of Autism. As a child, I would run (or bolt) very fast to clear my head or get away when distressed. But my running was discouraged, as nobody could keep up with me. As an adult, I have developed a very good life, including regular walks with a series of companion dogs. But I have missed the running.

This past summer, my good friend Dr Joan Jory of Guelph who advises me about health and nutrition, suggested that raising my endorphins through running could improve my health and sense of well-being. Joan is a distinguished marathoner herself, having completed the Boston Marathon last May. She put out an email call to members of running clubs in Guelph who might be interested in being my running partner. As a result, I met George MacNaughton, who has been my running partner since early September.

George is a very nice man--patient and understanding—who inspires me to do my best. I like walking very much as well, but the energy rush that happens when running is an entirely different peace that comes within me. I would like to run every day and aim to run in a marathon.

Recently I composed this poem to express the joy and peace I feel when running. I hope it may inspire others!

Andrew the Runner, Man of Peace

Running is a way for me to go with my feelings.
I think it helps clear my head for good thinking.
Yes, running is an avenue to freedom for me.
It is a way to make connections with new people,
and that connects me with myself more as well.

I feel like Andrew who runs,
not Andrew who is an autistic man.

I am free from the stress
of the sounds of home
and the hum of the world.
I just feel the sounds
of my own body and spirit.

Running is peaceful and calming for me.
I can free myself from all worries
and just run towards
the lightness of feeling
close to nature and God.

I feel a sense of being freed
from all things that restrict me.
I am running to me.
I feel so much better as a person
with the ropes of autism broken from me.

I am Andrew the runner.
I am Andrew who has hopes and dreams.
Andrew the runner,
now closer to being free and just me.

I am feeling inspired to share this
with my Bridges friends,
so they can also be free from the ropes,
and just be who God intended them to be--
themselves.

I think then people will accept us more
if we accept ourselves.

Running gives me a sense of peace,
that you can only achieve
through loving yourself
and the wonderful creation you are.
I am running towards this person,
Andrew the runner.

I am Andrew the runner.
I love feeling this peace.
I can only run faster and harder
to find the runner in me.
Then I will be at peace.

I am Andrew the runner.
I want to run fast and furious.
I am challenging myself to be
a man of full potential,
and that includes my peace.

I am running to me.
I am Andrew the runner.

-AB, 16 October 2009

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LIFE WITH AUTISM IS LIKE 'A BAD MOVIE SCENE-- WITH ME AS THE ANTI-HERO'

*National Post, Letter of the Day, Saturday, October 31, 2009
Re: Mother 'Couldn't Accept' Plan For Son, Oct. 27.
By Kevin Vasey, Petrolia, Ont. Reprinted with permission.*

I am a man with Autistic Disorder. Also known as classic autism, this is probably the same affliction that beset the unfortunate teenager, Tony Khor, with his mother now accused in his death.

Several things came up in the article regarding people's understanding of autism. It was reported that the boy was "a low-functioning autistic unable to speak, often making noises in an attempt to communicate." I would fit this description also. I have low muscle tone and movement difficulties, so I cannot verbalize. I communicate on my voiced computer and it terrifies me to imagine where I might be today if I had not been assisted in learning this skill.

"The boy's autism was so bad it often spooked people who were not familiar with his condition." I have many obsessive-compulsive behaviours, including pica (a medical disorder characterized by an appetite for non-nutritive substances) that must be alarming to onlookers.

"The boy would grow agitated around visitors no matter how often they came to visit." People with classic autism have hypersensitivity to sensory stimuli and difficulty with relationships. When friends and family visit, I want to interact with them but my body won't co-operate. Moreover, I become frustrated and anxious in such situations. Often it seems like I'm looking in on a bad movie scene -- with me as the anti-hero.

Not only must the law continue to protect disabled and vulnerable persons from abuse and death, but they need to be better understood. We also want the right to manage our own lives. For myself, I have recently left a group home to pursue a self-directed life. I will soon have a service dog that will be a companion and who will help control my compulsive behaviours. Personal support, training and ongoing education will be provided to enhance my independence.

Tony Khor and his parents should have known that they had options such as these.

BRIDGES NEWS

During 2009 we have been working on several projects to share the vision and values of Bridges with more people. Our next newsletter will say more about these projects. They include these two:

The BRIDGES VIDEO shows us all talking and listening to each other, and also using Supported Typing in other parts of our lives. We appreciate the expert help of Christine Zorn of PAN Video Services. The main section illustrates our vision and the value of our gatherings. There are also profiles of individual Bridges members, addressing these questions: "Who am I?", "What makes me the person I am?" and "What do I most need to support my good life?" We believe we are making a really good video. It will be distributed in DVD format. We hope to enter it for the Sprout Film Festival in New York.

Our IT expert friend Michael Jory has designed a BRIDGES INFRASTRUCTURE for our gatherings, so that everyone can hear and see what others have typed, and a true record can be kept. We need such a system as we are all hypersensitive to sound and one of us has severe hearing loss as well. We want the words to be spoken but also, very importantly, displayed, so we can reply to and discuss what others have said. The whole system has to work smoothly, without any distractions to disturb our thought processes.

HOW TO REACH US

Postmail: Bridges-Over-Barriers, c/o GSA, 16 Caribou Cres, Guelph, ON N1E 1C9. Please make donations payable to GSA, with "Bridges" on the subject line. Tax receipts are issued. Visit: <http://www.ont-autism.uoguelph.ca/bridges.shtml>
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