

BRIDGES OVER BARRIERS

Bridges is All About Friends and Connections

Our Bridges group gathers in Guelph for a day every 4-6 weeks, except in the winter. At our regular gatherings, with family members and friends, we use Supported Typing to talk about everything from spirituality to special diets. We share a meal and snacks and a walk. We view videos on topics important to us, and have shared other interests such as music, painting, and concerns about life transitions.

Guests and observers are welcome, and we ask all to observe this protocol:

Bridges over Barriers is a group that has been created by us as we grow as communicators. It is not easy for some of us to focus on typing what we want to say, and we need our visitors to respect our efforts. Please be aware that, during our morning and afternoon sessions, we the communicators lead the conversation while our parents and friends support, observe and record what we say.

Supporters and visitors do not speak during the communication sessions. You should know that what you say is understood by all the communicators who express themselves more freely in a positive and supportive environment. We hope that, if you are looking for evidence, you will see that we are a successful group of communicators. We will be happy to discuss your observations and questions during the breaks and by email afterwards.

BRIDGES GIFTS AND GRANTS

Bridges over Barriers is so important that we want to help more people to express their thoughts and be listened to with respect. In late 2005 we started a special fund, to which our families and friends have given more than \$22,000 in 28 months. We thank everyone for their kind gifts, GSA for administering the Bridges funds, Susan Honeyman and Andrew Foster as trustee-advisors, and John Verhart as GSA's treasurer.

The first special grant from the Bridges fund was made in 2007—to a Toronto man who asked for help for himself and his whole support team, to “learn how to use supported typing to express myself. I would like to learn how to respond to various communication partners and how to correct if they have said something that I don't mean. I want to learn how to initiate communication and increase my fluency in giving direction, choice making and participating in more complex social exchanges. I'd also like to add my voice to others that are working towards awareness, capacity building and advocacy for people of all abilities and needs.”

A second grant has been approved, for the sister of a Brampton communicator to train as a facilitator in workshops this month at the FC Institute, Syracuse University, NY. We hope to include a report next time.

Please consider giving to Bridges to help more people to express themselves and to increase public awareness of our rights and the benefits of Alternative and Augmentative Communication (AAC) and deep listening.

If you can give, please make your cheque payable to GSA (with Bridges over Barriers on the memo line) and send to: GSA Treasurer, 16 Caribou Crescent, Guelph, Ontario, N1E 1C9.

HOW TO REACH US

Postmail may be sent to the above address (Attn: Bridges). Send email to ebloomfi@uoguelph.ca (Subject: Bridges). For links to past newsletters, visit the Bridges webpage at: <http://www.ont-autism.uoguelph.ca/Bridges-2007.html>

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INSIGHTS AND INTERACTIONS AT BRIDGES GATHERING, NOVEMBER 2007

WHAT STRENGTHS CAN YOU BRING TO A COMMUNITY OF FRIENDS?

... My strengths are: I am smart, a great friend, happy and understanding.

... I am strong at listening, understanding and being myself.

... I am a good listener and respect other people's choices.

... I am patient and kind. I am keen to learn new things. I am understanding and ready to try new things. I am a farmer and do a good job at David's farm. I am gentle with people and try to listen well. I want to visit new places. I am smart and joyful.

... I think my strengths are in my willingness to try new things. I like to host people in my home. I have a lot to say and I am good at it. I do nice things for others. I am interested in the world, close to home and far away. I like to work for politicians and the environment in my area. I think one strength I learned from my mother is bringing people together.

WHAT STRENGTHS ARE IMPORTANT FOR PEOPLE TO SPEND MORE TIME TOGETHER?

... Hearing is important.

... We should all be patient and kind. We need to wait for each other to speak. We need to pay attention to each other.

... We need to be kind, patient, understanding and tolerant. It is important to enjoy each other and have a sense of humour.

... I think being patient with each other and our supporters.

... Important to be good and kind to each other and our supporters.

WHAT IS THE DIFFERENCE BETWEEN HEARING, LISTENING AND PAYING ATTENTION?

... Hearing, listening and paying attention are all different things. Understanding is the most important but I can't differentiate between them.

... Hearing is with your ears, but you may not understand. Listening is when you take it in. Pay attention, then listen.

... Hearing is listening with your heart. Listening is hearing the words and understanding them. Paying attention means focusing on the person who is talking.

... Hearing is with your ears; listening is with your heart; paying attention is using your mind.

WHAT DO YOU WANT THIS GROUP TO PAY ATTENTION TO AND UNDERSTAND ABOUT YOU?

... I have bad hearing so be kind.

... We need time alone and activities together and time to enjoy each other's company.

... I want you to understand that I like to talk and I need people to learn to FC with me.

... I think it's important they should know that I am a good person.

... I want the group to know that I am serious about Bridges and our friendship. If we live closer together we should be able to do it.

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ARE THERE ANY STRUGGLES YOU WOULD LIKE TO TALK ABOUT WITH FRIENDS?

... I am struggling with the people who do not use FC with me. I need then to talk with me. I am struggling to be in control with myself. I feel tense too. I do not know why.

... You should insist.

... You should show your displeasure. They must understand that you need to communicate

... I hear your sister is learning. That is a start.

... I want to tell them, but they don't listen.

They want me to be quiet and do nothing.

I have to accept that people need to support me. I have to be patient with the people that help me. I think learning new things takes time and patience.

... I am struggling with myself, and how to be with others when I get upset. I do not like it when I lose it but I cannot help it. It is hard to control myself and not know what it is about.

... I know that feeling too, Tim. It comes and goes. The diet and pills and exercise help.

... Are you feeling tense and out of control?

... I am not now but I was a few minutes ago.

... Can you take a break from people? Think calm thoughts and say a prayer.

... I am struggling with the idea of never being independent. Who will do interesting things with me when my parents are gone?

... I think we all struggle with this. That's why friends, and circles and Aroha are important.

... I think he is doing very well. He is my idea of a good man and I love him very much.

... I am struggling really hard to wear the hearing aid because it hurts to hear.

... I think it will improve as time goes by. I think you are doing very well.

... Keep it on a little more each day.

EXPLAINING BRIDGES TO OTHERS

How Supported Typing) has helped me

... I need FC to live well with others and they need to be able to use it.

... I have used FC for more than a decade. I guess it has made all the difference. My voice is heard now.

... My life is better because I can talk to people. I can tell people what I want. I can share my dreams and talk to my sister. I enjoy talking to her very much. I am happy that I can talk to people. I have a support group to help me follow my dreams. I get to work at the farm and talk to --- and ---. We share ideas about the farm and have a good time together.

Differences between Supported Typing (FC) and Copy-typing on a Computer

... I need the support to do spontaneous typing.

... I am in the mood when someone touches me to facilitate.

... I can spell because I know the words and I need support to focus on my spelling. Yes, I need the touch to focus on the spelling.

... Our tactile defensiveness is strong but FC gives us firm support.

Why it seems hard to look at the letters while typing with support

... My senses are scrambled--not like yours

... I don't look at my keyboard [all the time] because I don't need to. Sometimes I look at the letters. I know where the letters are.

... It is hard to see things when looking straight at them. I do look sometimes but it is hard. It gets distorted in my eyes. So I glance and use peripheral vision. I see parts, not like a whole thing that belongs together. It is hard to look and listen at the same time.

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OPPORTUNITIES MISSED, BY J. KEVIN VASEY

I feel that I have missed many opportunities in my life because I am perceived as incapable. People do not take my requests seriously even now.

When I was in high school, I thought that I had an interesting career ahead as a writer or an artist. But I have been sentenced to working in a laundry for many years. I'm limited to what support people are able and willing to do with me.

They say I am very good at what I do. My reward for excelling is more of the same. I have not received a promotion or an opportunity for advancement. I want someone to hear me. I resign! I resign!

It is time for my life to take a new turn. I will be an artist and I will experiment with paints and clay and whatever else is out there. It is difficult when I live with two other men whose tastes are different and only one support person is with us. But my parents are arranging some opportunities for me.

One thing I am proud of is my book, ***The Road Trip: Life with Autism***, which was co-written with my mother. Someday I will write another book about ***Life Further Down the Road***.

My mission is to plead for the voiceless people. There are so many who are not being given a chance at true living.

These are people who are not given the opportunity to express themselves. Their entire lives are opportunities missed. Their parents, teachers and support people do not have faith in them.

Perhaps it is fear on their part: fear of failure or fear of discovering what life has denied the voiceless person they love.

My life is really very good. I have my family, my housemates and my special friends who use supported typing to share frustrations and successes. I have support workers who enrich my life with various therapies, excursions and recreational activities.

I love to travel, have been twice to Europe and all over North America. I love being in my motor home with my parents and look forward to a long life of adventuring.

But I will become more creative when I have the chance to work with art materials. It will increase my independence and feelings of maturity, value and giftedness. Perhaps it will open another door to helping others.

It is my dream to have my own living quarters and to spend more time with my brothers and their families.

I believe in God and communicate with him freely. I do not need supported typing when God and I talk to each other.

I am a man of worth and dignity and require power over my destiny.

Kevin's first book is *The Road Trip: Life with Autism*, by Gloria Pearson-Vasey and J. Kevin Vasey (Ottawa: Novalis, 2005). ISBN 2-89507-603-0.

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WHAT EVERYONE YEARNS FOR: REALLY GOOD SUPPORT TO COMMUNICATE...

by Andrew Bloomfield, who thanks several friends including Richard Attfield of England for their comments.

“Typing to talk” has enabled me to have a much better life. I need more supporters so I can choose and comment on priorities and sustain my good life into the future. I also want to help others who cannot speak with their voices to express their thoughts so that people listen, understand and respect them. That is the vision of my dream for Bridges over Barriers.

I have lived with quite severe symptoms of autism for almost all my 40 years. Since 30, I have also had occasional seizures and spells of pain and turmoil when I cannot control my body. But I am naturally the most exuberant person I know. I was introduced to Supported Typing (what we used to call Facilitated Communicating or FC) in 1991, when I was 23.

Though I seldom speak with my own voice, I like to use the simple words “talk”, “speak” and “say” for my communication through typing. The devices on which I type have voice synthesizers, so I and others hear me speaking through the computer voices. It has always been very important to me to have a device with a voice. I now use a DynaWrite for supported typing, while on my desktop computer I type without support in WriteOutloud software. I read and copy text independently and so learn new ideas and information. I take them in through my eyes, my fingertips and my ears. I feel good about typing independently: it exercises and stimulates my brain. But I still need physical support to “type to talk”—to compose and express my own inner thoughts. Who knows if my copy typing will lead to independent “typing to talk”?

Supported Typing has brought me respect from others. Before I could type to talk, nobody really

could know what I was thinking. I communicated as best I could by some signs and by pointing. But it was so limiting and unreliable. I was impeded by my movement disturbances. I could sign for things I needed, but I couldn’t say what I thought and felt.

When I was about 6, some experts thought I should learn Signed English rather than be taught to speak with my voice. I understood this might help me to be “heard”, so I worked very hard at signing. I learned about 2000 signs, so that my teachers called me the walking sign dictionary. However, it didn’t really go anywhere, because too few people in my life would sign, and also because the signs were mainly for basic needs and objects, rather than ideas. And then sign went out of fashion. Later, I did not much like picture exchange cards, as they seemed demeaning. The pictures just showed objects, not thoughts.

Before Supported Typing, other people probably saw me as a primitive childlike person who was not a thinker. I know it must be hard to respect someone who paces and screeches, but says nothing intelligent. Some may assume that people who do not speak cannot think. People may have respected my dignity, but not my mind. I feel that, when I had a reliable way to type real thoughts, more respect came my way.

I would like people to know that I am trying to be in control of my body, even if it looks like I am sometimes not. When my body goes in the opposite way from the way I want, I must try to keep calm, even though I feel upset. From the outside, people only see my racing and pacing. Not my inner struggle. I hope that when I hold my ears, they can understand that I am really working to hold in the storm. It’s not usually

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that my ears hurt. I may hurt somewhere or noise may get on my nerves. Supported Typing lets me tell people when my body is acting up. I sometimes express my thoughts in poems, like this one:

What it's like to be me (29 January 2003)

I'm a bundle of sensations:

I get the urge
to touch and pick,
and I must follow my urges.

Can you see my urges?

I can't tell you:

I just show you.

I'm a bundle of nerves,
and a jumble of thoughts.

I'm in constant motion,
and my mind's always going.

I wonder what it's like to be you.

Do you wonder what it's like to be me?

I'm a time bomb waiting to explode,
and a tear waiting to fall.

I remember being a little boy and wondering why Vickie (my twin sister and best friend) was getting things that I didn't. I mean that she could do things while I was still thinking of doing them. One example is playing. I would want to join her, but could not move there until she had left off and moved to something new. My body was stuck. I was trying, but ended up running around and jumping. It became important for me that she could get things for us and talked for us both. It became clear to me pretty early on that she was more in the world than I. I struggled to be in the world she was in.

Whenever I could, I looked to Vickie for a lead as to what I should do in a situation. I might not understand exactly what was happening or why we should do something. But I found it was

better to follow her lead. She would look out for me. I remember that I learned about humour and irony by listening for the tones of voice when my parents and Vickie talked. I liked to join in the laughs and smiles. At school, when I did the right thing by copying what others did, my teachers would say "He's only cueing; he doesn't really understand." But that was the way I learned to cope.

From 1991, Vickie was my key facilitator with Supported Typing. We travelled to many places, before she died in an accident in 1996. I called Vickie my window to the community. I think of her every day. It is most painful around the time of her death. It is in my heart the times we shared.

I think that my parents knew I was more than I could express. They talked to me and tried to understand my ways of coping. I taught myself to read from about two, before school, reading books with Mum or Dad. Vickie and I would sit on either side, and follow the printed words as they were spoken. It felt like a world of mysterious words that I could enter. A favourite activity was to read through big dictionaries which had little pictures to go with the words. I still love to read the many books and magazines in my home.

But I have felt that others pitied me. Nobody can respect you if they pity you. At school my teachers expected so little of me. I might have learned more if they had respected my mind's potential. The Principle of Least Dangerous Assumption proposed by Dr Anne Donnellan in 1984 says that it is better to presume competence. This means that it is more dangerous to assume a person doesn't understand than to assume he does. If my teachers had understood the principle, they

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would have given me more opportunities than just doing easy puzzles and tying shoelaces.

Supported Typing is so liberating. I was locked before it. I had to hope others would see in my eyes and behaviour, but these were not reliable. I saw that nobody really knew how smart I was, but I had no way to express myself. It felt like I was observing my own life but not controlling it. When others did not understand me, I was sad and frustrated and agitated all the time. I got angry. I was hopeless: I never expected to find a better way. A few people really looked inside and past my autism. Until Supported Typing, I did not know I thought in words that others could understand; I was just absorbing their words.

I remember the first time I used Supported Typing. It was with Martha. I remember trusting her and letting her show me pictures and ask questions. I pointed to and typed the right words. I spoke for the first time in words that made sense. I was very surprised by Supported Typing. Now I really knew I could spell and read, and other people saw it too. Now I had thoughts. Now I could talk. The thing everyone yearns for is really good support to communicate.

My life now is excellent. I have my own home and it revolves around me. I know everyone who comes here is friendly to me. My parents, my circle of friends and my housing trust listen to me and respect my choices. I am comfortable and safe here. My garden is heaven on earth. My dog Amy is my friendmaker. I'm happy with our progress. Well planned and not stressful. I grow into each step. All this is possible because I can talk through typing.

When I had been using Supported Typing occasionally for two years, a friend asked me to

“speak” to a room full of special education teachers. Vickie drove me with my Epson communication device to Hamilton, and two of my friends were there too. My device had a voice, and the words I typed were also projected on to the wall for all to see. I had prepared things to say and also answered questions the teachers asked me. My main message to them was “Autistic children are smart: teach them to read.”

For the past seven years, Beth has regularly visited my home for Supported Typing sessions when I can reflect on my life. She is a very good facilitator who gives me both physical and emotional support. I wish that others could have this kind of help. Since early 2004, I have hosted regular gatherings of communicators. In May 2005, after seeing *Autism is a World*, I felt inspired to think of starting a place of refuge and organization for communication support and life planning for people who live with autism.

We have named our communication group Bridges over Barriers. It is about building bridges, not walls. I love the image of a bridge--like that of a door or a window. Supported Typing is not a “cure” for autism, as some people thought it might be. I am not interested in a “cure”. Supported Typing is a bridge that takes me from my island to the mainland. I think I am visiting the mainland, not living there, and visiting is fine.

Our friends, when asked to support the dream of Bridges over Barriers, have been very generous. We now have some seed money and want to offer grants to make good things happen. (See more on page 1).

In My Mind: Thoughts and Words of Andrew Bloomfield was published in 2006.

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THE BEACH *John Morris-Dadson, 2004*

The beach was calm and serene
early in the morning.
The water was moving very very little
towards the seashore.
The sand was as fine as grains of salt
under my bare feet.
The air smelled of seashells and sand.
The sky was a clear soothing blue.
A feeling of peace permeated the air.

Note by John's mother Anne:

I have a book of John's writings over the years beginning in 1992 when he first started using FC at age 9. When I first discovered, with Beth's help, that John could communicate using FC, I advised his teacher at St. Monica School. At the time, John was in a small segregated class with

hearing impaired children. His teacher began giving him topics to write about on a computer and would print his work and send it home for me to read. I kept most of them and it is interesting to see the progress that he made over the years with different facilitators. The teacher sometimes gave John a photograph or a newspaper article to write about. The results were amazing and often very funny. Initially his writing was hard to decipher but gradually became more intelligible.

When John was in grade 6, there was a writing competition at the school and John expressed a desire to enter it. He had a wonderful facilitator at the time who worked with him over a six week period. John wrote a wonderful essay on FC. The participants sat on stage in the school auditorium and took turns reading their essays for the other students and parents. When it was John's turn, one of his classmates stood beside John and read his essay. It was a great moment. John was very proud to have been involved and wore his participant ribbon with pride.

Why I Love Bridges

(13 December 2006)

I want to tell people
that I love Bridges.

It gives me a focus
and centre of interest,
a cause that is important
because I believe in myself
and my friends.

I think the spiritual connection
between us is hard to describe.
I know I feel it.

It is family and godly.
I do think we get ideas
from each other.

Who knows where it begins,
and where it ends?

Supported typing helps us...

... To look forward, plan for good lives, and make choices

... Life planning means our voices. My circle does nothing without my voice.

... It is good to be able to talk about things with others before they do things for me. I need FC for interviews with new support people.

... Before supported typing, it was terrible to meet new people who were supposed to support me.

... We can only initiate conversation with supported typing.

... Supported typing is very hard, a strain on my body and mind.

... But it is good to do it and I am glad I can.

Communicating....

...is opening your mind to let others inside to know you and what you think and believe and feel. It is as if the more I communicate the more I think.

... makes me feel like a door opens so the world can understand me and I have a chance to be in the world. I mean out in the world as I am who I am. Before Supported Typing, I had ways that were just for basic needs or pointing to something. That was not always reliable. I want to tell my friends to say how good I feel when I can say what is in my mind.