

BRIDGES OVER BARRIERS

IDEAS AND INITIATIVES

Bridges over Barriers is three years old!

Bridges grew out of the regular gatherings from January 2004, of some friends who use supported typing rather than their voices to express themselves. Before then, I had been using a bridge as an image of how my way of communicating could connect my island to the mainland society and overcome the frustrations of being misunderstood and not in control of my life. These ideas were inspired by my joy in working with my special communication partner Beth from 2000, and strengthened by the gatherings of communicators I hosted during 2004 and 2005.

When I learned how to communicate in a new way, when I learned to use supported typing [aka FC], I had a whole new world open. I knew I could think and was smart. Before that, I had no way to tell anyone except my eyes and behaviour: I was angry, frustrated and worried a lot. Now I have a way of communicating and though I am still autistic, life is better (December 2003).

In midsummer 2005, I described my dream of a place of refuge and organization for communication and life planning for people who share the challenges of autism to come together to share support, ideas and community. By October 2005, we were using the name Bridges Over Barriers for the vision of helping new people to communicate effectively and thus improve their lives. I appealed to my circle of friends:

Please consider giving your support to the new project my family is participating in. Bridges over Barriers is the beginning of an idea for us to build on a small community of adults with autism who have been meeting a few times a year since January 2004. We have been developing our skills as communicators and sharing technology ideas and friendship. We want to extend this community to help more people to express their thoughts and be listened to with respect. We would like more opportunities for others to benefit from our experience, and to encourage and train more people to support those of us with communication and movement disorders (October 2005).

Guelph Services for the Autistic, the not-for-profit corporation of which I am an active member, agreed to shelter donations to Bridges Over Barriers. As a registered charity, GSA can issue tax-creditable receipts to donors and hold funds in trust for worthwhile purposes. Two professionals, friends of Bridges, advise the GSA directors on worthy projects that should be helped, and the GSA Treasurer and Board have been wonderful. Friends and family have been generous, giving about \$24,000 already. Some gifts were in honour of the long lives of two Bridges grandfathers.

From spring 2007, we proposed some ideas of how Bridges funds could promote more listening to and respect for people who do not speak with their voices:

- Materials and events to increase awareness of supported typing and deep listening
- Information for family members and friends, so they know for sure that communicators are expressing their own thoughts
- Reaching out to new communicators
- Training and practice for person-plus-team in supported typing
- Recruiting and training new communication partners, individually or in groups
- A major event, like a conference with workshops, for all people who care or are professionally concerned with supported communication
- Our larger and longer-term dream of “a place of refuge and organization for communication and life planning.”

Continued on page 2. See also note of other items in this newsletter.

BRIDGES OVER BARRIERS

IDEAS AND INITIATIVES *continued*

The first special grant from the Bridges fund was made in August 2007—to a Toronto man who asked for help for himself and his whole support team, for formal training to learn how to use supported typing. A second grant enabled the sister of one of the Bridges men to train as a facilitator in workshops in April 2008 at the Facilitation Communication Institute, Syracuse University, New York. Please see her first report on page 7. Bridges funds have also bought DVDs produced by the FCI as well as WriteOutloud software for the use of Bridges members and contacts.

Bridges is open to more applications from individuals. At present we are thinking about three related projects that we would work on together. All of them would help us to have more choice and control in our lives through supported decision-making. Read more about this on pages 8 and 9.

1. A BRIDGES OVER BARRIERS VIDEO, that would show us all talking and listening to each other, and also using FC in other parts of our lives with our families and friends. The video could also explain a bit about how important this is for us and for others who cannot use their voices but have plenty to say. We are inspired by the video made by the Brotherhood of the Wordless in Brisbane, Australia, some members of which visited us in May 2007. See page 4 for more of our ideas about this movie or film.

2. A BOOK AND INFORMATION PACKAGES with advice about our need for support to type and to express ourselves. See more on page 5. The book/packages would include parts about:

- Our right to communicate in our own way, using AAC (alternative and augmentative communication) if we cannot use our voices
- Our responsibility to think about options and make choices about our lives
- Some context about other ways we communicate and are listened to, and how FC or ST may be most reliable
- Information about FC/ST, so other people understand that it is really we who are doing the thinking, pointing and spelling, while our supporters steady our hands and muscles so we can express what we really think and mean. This part could include advice from the experience of other communicators who have managed to become more independent typers.
- How important Bridges Over Barriers is to us, as a community of communicators.

3. We also need BETTER TECHNOLOGY FOR USE BY GROUPS OF COMMUNICATORS, so that everyone can hear or see what others have said, and a true record can be kept. This would involve linking our communication devices together and with a laptop controller in some kind of wireless system, and then projecting the words on to an electronic whiteboard to be displayed and spoken out loud very clearly, as well as saving them to be stored in computer files, and shared around by email and in print. Such a system is needed by our group 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. We have put out this idea of what we need to friends and contacts of friends, and have hopes that we will be offered some expert help. Whatever system can be made to work for our needs will also help other people who use AAC to speak their thoughts.

Also in this newsletter:

Page 3-5: Insights and interactions at our gatherings in May-June-July 2008

Page 6: Ken's story about David's Farm

Page 7: Learning to listen: Donna reports on Syracuse

Page 8-9: Supported Decision-Making for more choice and control in our lives

Page 10: Resources; giving to Bridges, reaching us.

BRIDGES OVER BARRIERS

INSIGHTS AND INTERACTIONS AT BRIDGES GATHERINGS IN MAY-JUNE-JULY 2008

Does the label of “autism” help us? Some people say that “autism” suggests stereotypes that may get in the way of our growth and relationships with others.

--I think the label of autism is okay because that is what we are and they can go jump in the lake if they don't like it.

--I like what Tim said. Also they can see it and may know better what our needs are. Aspies get more lost in the crowd, and are maybe not as obvious.

--Labels are good. We can get support. People are intelligent not stupid.

--I think it helps to know I am autistic because then people can help me if they know what my disability is. In the past no one knew anything about autism so they couldn't help me. I didn't get a good education because I was not helped to focus and sit still and learn from the teacher. I was not looking at people in their eyes, so I didn't know they were talking to me and I didn't understand how they felt because I didn't look at their faces. I missed living with my family because I couldn't behave right. I had to go to a place where handicapped kids went to live. I didn't like it there because everyone was handicapped and could not talk or do anything that was fun.

--It's great that everyone agreed the world should wake up and accept us as we are.

How to cope when familiar friends and support workers leave us?

--You can help me cope by talking about the changes. You have to help me keep going because I get stuck and cannot move. I appreciate people encouraging me to accept the changes. Help me think something positive about the change.

--I think it is hard. But it is good we love each other.

-- It is a hard life. Sadly we must cope. I have had many people leave to go somewhere else. The only way to cope is to keep going and keep routines consistent.

--Keep going. I am just beginning to understand.

--I think we keep going by being ourselves and not getting mad at the world.

--I think firm encouragement and watching my diet help me to get in motion.

--I am happy that my Bridges friends are here to encourage me. Thank you for listening to me. I need your help now. I am OK. I will learn to take care of myself. I will learn to type by myself so people will know what I want. I will do well at the farm because I like being there. I will behave well because I want people to like me. I will be calm and patient so the new people can learn to take care of me.

--Nice attitude.

What is each of us doing to help the planet? Could we do more?

--My idea is that we could do something together. Like planting trees. Buying from farmers. Use more over again. Maybe a poetry book to raise money for the planet and Bridges. You might say it is all about the world and how we fit in it. Not bad to show we don't just receive. We give too.

--We help the planet at the farm by recycling the food bits into the compost heap. We give the cats leftover food from our table and we put the manure from the horses on the garden to help the vegetables grow. XX used food bought from local stores. He buys Canadian food and things from the area he lives in. I try not to waste food. I eat my food from the table. XX recycles paper into the grey box and the cans and bottles into the blue box. I try not to throw paper down on the ground. I don't like seeing garbage on the lawn.

--I think we need to get political for ourselves and get our views in the news

BRIDGES OVER BARRIERS

INSIGHTS AND INTERACTIONS AT BRIDGES GATHERINGS

What to do when we know what to do but can't get our body and muscles to co-operate?

- I am very agitated. It is very hard to communicate when our bodies are uptight.
- I start to type and my ideas come to me. I like to talk and be listened to. I still try to type when I am stuck. I focus when I get started. I will try harder when I am stuck. I like to shake hands and practice that as well.
- I think that if people are in tune with us that they could help us more.
- I need to be asked. Remind me often to talk to find out what I want.

How do we get other people's attention to help us when we are stuck?

- I mean show others if we need help. I need ideas to get attention in a social way. Or I can get excited.
- I take Mom's hand and I touch the computer for Mom to get ready for me. I also point to things when I want help. I go to the workers and bring them to what I want to do. I look at people and they look at me to see if they can help me. I need to be reminded to look at the board and to look at people's eyes when I am out in social situations. I need help to be with people by doing a story first about the visit.
- It is important to give support workers time to know us.
- They should tell me to use the computer and I tell them what I want. One night I was awake with a migraine, but nobody asked what was wrong.
- It would help if we were in the room together and we could practice to be ready
- I like the ideas of role playing and the social story.
- I need help reading people's faces and understanding how they feel about things.
- I need a mirror to see what my face looks like. People get confused by my body language and facial expressions. If you look in a mirror, you will see angry, smiling happy. I recognize other people's facial expressions, but not my own.

How do we get more acceptance of Supported Typing/FC?

- We can have people learn to support FC.
- I think that I do feel that.
- We can type in front of people so they can see us typing
- We can invite people to talk with us and take courses...
- We need to make a movie and send it around the world like Rodney's friends in Australia.
- Yes, I would like to have a film made of us. People could watch the film to learn how we type.
- A movie is a good idea. Better to show how smart and close we are together.
- I think you can get a friend to do it. Film the gathering and in our own homes using FC with our families and friends. It would be good to show how we support each other. Break some stereotypes. I do want to make a film to show that we very much like to sit and talk and be together, even though people think we are not social and won't permit touch.
- A great idea to teach people about our joy in communicating with each other. I hope we do this, so I can take it to Nova Scotia and start a group there.

For whom would we be making this film?

- Everyone, even the families, should know that our lives and thoughts are normal.
- For people who don't think we have thoughts of our own.
- We show that video to people who want to learn to FC with us. We show it to people who don't believe in us to prove we can talk and that we are smart and can do things.
- Everyone
- Our support circles and sceptical and negative thinkers who are working with autistic people

BRIDGES OVER BARRIERS

INSIGHTS AND INTERACTIONS AT BRIDGES GATHERINGS

A key goal for Bridges is to produce really good resources about our rights to communicate in the ways that are most reliable for us. Video is just one way. We could also make printed materials. What do we want people to know?

--People have to understand that it takes patience and perseverance for us to explain ourselves, and that signs and symbols don't cut it.

--I would like to say that I am very glad that I can use FC and hope others can too. I can help them.

--think we should tell them we talk using FC. They need to accept that we talk with FC and not with our voices.

--I enjoy being here. I am calm and happy to be here. I like talking to the other men. They are my friends.

--How about we write a pamphlet while Beth makes a material packet with the facts and myths? I might want to write a narralogue about our group, how we started and how we work.

--Use all the thoughts we have shared today and the other times.

--I would tell them about autism and how it affects us. I would tell them that we need support to talk and help to live our everyday life.

--I would tell my story and explain what I need to communicate—what works and what doesn't.

--I would explain that we type to speak. We listen to each other and then we type our thoughts to each other.

Idea of New Technology system to connect our devices, project the words on screen or wall, and also keep a record

--I think I will type better since I will see my typing on the screen.

--I think it would be good to see everyone's words.

--Yes, a good idea.

--It will be nice to have the text. I wonder if my tightness will go away. I'll need to be more accurate. To be more accurate, I need to look more at the keyboard and screen.

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 OVER BARRIERS

KEN'S STORY ABOUT DAVID'S FARM

I can tell a story about working with the horses. I think the horses look forward to seeing me because I feed them carrots, hay. They are calm and wait for me to do things for them. I enjoy seeing them every time I come to the farm. We like doing things together. I think the horses enjoy living here because we take good care of them and they like staying here very much. Don comes here to give them their carrots and we enjoy giving them to them. I think the farm is a great place to live because it is calm and peaceful here. I like the countryside because we can relax and be ourselves. I think country people are kind and happy because they get to work with animals and get to eat good food. I like the pets like Tickety because she is friendly. I like the other cats too. They are cute and friendly to see. I like working with Dad. We are a team and Dad likes working at the farm. I like being with Dad outside. I like this house very much. It is comfortable and cozy.

I will talk about working in the barn. I like doing the hay and straw. I like feeding the horses their carrots. Just like every time I open the barn door, Heidi knows I think I might feed her. By the time she has carrots, her tail is up. I think she is ready to poop. I run away smiling inside. Do you see me smiling getting away from the pooing. Feels good to feed Heidi. I like her. I look at her in the stall.

The horses are very friendly and they go to the barnyard. They like to roll over in the mud. They eat lots of carrots and hay. Then they have to go to the bathroom. They like to go outside to drink water.

I will talk about working in the barn. I like working in the barn. It has lots of animals

living in it. The sheep bah when we come in. The horses put their heads out for us to pat them. The cats follow us around. I do work in the barn with Dad and Donna. We clean out the stalls and feed the horses carrots, hay, and straw.

Peter collects eggs from the hen house. Sometimes I feed the hens their grain and sometimes I collect eggs. I help Don with the carrots when he brings a truck load to the farm. I help bring water to the horses and I give them oats to eat sometimes. I will be happy at the farm today. We will work hard for David and help Peter to work too.

I want to tell about the cats. I like Tickety greeting us when we come in to the house. I like the other cats outside when we drive up in the car. They are waiting for us. I think the cats wait for us to come. They stay in a group together when we arrive. They hope we are going to feed them. The cats are pretty colours. I like the black and white fur. They are interesting to watch. They follow us everywhere in the barn. They wait for Mom to feed them their cat food. They are happy to live here. They can stay together in this farm. I want to have animals as pets someday. I want a dog and cats to live at my farm. The dog's name is Sam. Sam would follow me around while I work as company. I think the dog should have stayed here. I am not afraid of dogs. They usually wag their tail when they see us.

I will talk about the work in the kitchen. When we arrive, we say hi to David and Peter. David makes the tea for Mom and I then he makes coffee for Dad and himself. We sit in the living room and talk to each other. I talk to Peter and Dad reads a poem from David's book. Sometimes Don comes by and he has tea with us.

BRIDGES OVER BARRIERS

LEARNING TO LISTEN

Bridges' second grant enabled Donna Moon to take part in a training event in Syracuse, in order to help support her brother's communication. These are her impressions.

In April 2008 I had the opportunity to go to the Institute of Facilitated Communication at the University of Syracuse to attend a two-day workshop on Facilitated Communication. Unsure of what to expect, I was pleasantly surprised by the informal and intimate gathering. Located in a small conference room, an eclectic group of thirty or so people gathered in small groups at round tables. Those present included professionals, parents, students and individuals with autism. I found the two-day workshop to be engaging, informative, practical, motivating and most importantly inspirational. The format consisted of practical exercises mixed in with teaching, open forums and large and small group discussions. Both instructors shared their personal experiences as Facilitators. Also, three individuals with autism shared their thoughts, on how it is to communicate through Facilitated Communication, throughout the workshop and talked about how their communication improved over the years.

The workshops stressed the importance of practicing proper technique and best practices at all times. I learned several new practices that will aid me in being a better Facilitator as well as creative ways to stimulate conversation. However, the most important thing I learned was that it is the relationship between the Facilitator and the Communicator that forms that basis of successful communication. A strong relationship that is built on mutuality, trust and support becomes even more important when helping the individual with autism move towards independent typing. I found it especially encouraging to learn that it was possible for all individuals with autism to learn to type independently. The main requirements were that the person with autism must want to move towards greater independence and that they must be ready to do so.

A young man with autism (now 21) shared his struggle towards independent typing and what helped him achieve this goal. He can type his thoughts independently on his communication device and then read them aloud. He told us how achieving independence was a long and hard journey--how even though he wanted to be more independent, he still craved the extra support of the Facilitator and was reluctant to leave it. He said that it was the supportive, open and trusting relationship with the Facilitator that was essential for him to move towards independence.

My experience in Syracuse encouraged me to continue working towards better communication with my brother. The workshops reinforced that learning to be an effective Facilitator takes time and is not something that happens instantly. The key is to establish a relationship of support and trust and also to start with setwork, simple questions, and work towards freer conversation. My ultimate goal is to be able to have a spontaneous conversation with my brother, where Ken is able to freely share his thoughts, feelings and opinions with me. This is Ken's goal as well, and prior to my attending these workshops, we both were feeling somewhat frustrated at not being at this stage yet. I learned that reaching this stage takes time and patience, but with perseverance it is achievable.

BRIDGES OVER BARRIERS

LISTENING TO EACH OF US: SUPPORTED DECISION-MAKING

How do we ensure that our real wishes and values are respected? As Adults with Autism, we communicate in ways that other people do not easily understand, so they may stop “listening” and may doubt our intelligence. Our parents and friends may speak up for self-determination and want to respect our tastes and preferences. But in practice our parents and caregivers may also be afraid we will come to harm if they let us take risks. Or some supporters may be so keen on choice that they would remove all safeguards, so that a person who does not speak could be exploited.

How can we be protected from danger, but also have room to grow and express our individual personalities? One way to both keep vulnerable people safe and also respect our choices as “the authors of our own lives” is through a Supported Decision-Making Agreement. This has many advantages. But most importantly, it recognizes that we think and want to make our own choices, and that our ways of communicating must be respected and supported.

Almost everyone has some kind of support in making decisions. People who speak and cope easily in the real world usually make decisions in collaboration with others whom they respect and trust. You ask advice from experts in various fields and trust their recommendations even when you do not fully understand financial, legal or medical intricacies.

So the only real protection for us who are vulnerable because of disability is the quality of the committed relationships we have with our friends and supporters. We need a circle of trusted friends, ideally incorporated as an Aroha

entity of personal empowerment and support, who respect the way we communicate and make choices. Their commitment to us can be expressed in a Supported Decision-making Agreement (SDMA).

An SDMA should be set up while parents are still alive to support the process. Other ways of planning for us can have great weaknesses and be based on false assumptions—for example, depending only on agencies or the government, or legal guardianship, or even leaving everything to what parents and siblings imagine we want and need.

Parents often don’t realize that they cease to be the natural legal guardians of their sons and daughters when we turn 18, the age of majority. For parents to continue as our guardians, we must be judged incapable by court order and a guardian appointed to make financial, medical and legal decisions for us. The drawbacks of guardianship are that all decision-making power is removed from us, and all citizenship rights, so that in the eyes of the law, we are no longer persons. Obtaining a guardianship order is also costly and time-consuming.

It is possible for us to be safe and have our choices respected without resorting legal guardianship. In *A Good Life* (2000), Al Etmanski declares that supported decision-making for a person who is vulnerable because of disability means:

- We actively participate
- Our views are sought and taken into consideration

BRIDGES OVER BARRIERS

LISTENING TO EACH OF US: SUPPORTED DECISION-MAKING

- We are surrounded by knowledgeable, caring and trustworthy people who can assist with our decision-making, support our communication, and listen to and interpret our decisions
- Our needs are the primary consideration, not those of the staff or service system
- The focus is on our abilities and wishes
- All our choices and options are considered
- Our tastes, preferences, motives and ability to discriminate are taken seriously
- Our risks, failures and mistakes are recognized as learning opportunities
- Our intuition and feelings have as much weight as our intellectual ability
- All our methods of communication, both verbal and non-verbal, are recognized as valid.

There are three broad areas of decision-making for a person with a disability:

- Health/medical
- Financial
- Personal care

A durable/enduring power of attorney is a good idea for the first two areas, but a more comprehensive Supported Decision-making Agreement (SDMA) fits with this too.

An Aroha entity of personal empowerment and support fits perfectly with an SDMA, with three or more non-family directors sharing knowledge and responsibilities for health/medical, financial and personal care matters, and able to advocate and request services of a monitor.

REASONS FOR MAKING AN SDMA:

- The process is powerful and useful in helping a person to become accustomed to making decisions.
- The SDMA is a tool to strengthen existing relationships, involve others, and thus help a personal support network to grow and increase its commitment to the person. An SDMA provides status to family and friends and involves a broad group of people who reflect the focus person's multi-faceted nature.
- The SDMA says that decision-making assistance will be based on a person's values, beliefs, experiences, preferences—and not on what is perceived by others to be the person's best interest.
- The SDMA identifies the ways in which the person expresses preferences, makes choices and conveys understanding,, and if necessary witnesses who are expert in that system of communication and/or know the person well.
- The existence of a SDMA creates at least moral authority for assisted or supported decision-making. If enough people make SDMAs, the moral authority will influence legal authority, as with “living wills” and “health care consent forms.”

Read more: Al Etmanski, *A Good Life* (2000), chap 5 “Ensuring Choice,” pp.178-225.

Guelph Services for the Autistic, *Creating a Home and Good Life of My Own* (2008), Section A: “Listening to the Person” (pp.A1-A8).

BRIDGES OVER BARRIERS

BREAKING THE BARRIERS was a powerful initiative funded by the Nancy Lurie Marks Foundation and administered by TASH 5-6 years ago. Its vision and values are very relevant to the goals of Bridges over Barriers.

OUR VISION...

- That all people with disability labels, who do not communicate through speech, have means of communication which allows their fullest participation in the world; that people can communicate using their chosen method; and that their communication is respected by others
- People who have disability labels, and who use alternative forms of communication, will be active at the local, state, and national level in shaping public policy.
- Facilitated Communication will be accepted in practice and policy as a legitimate augmentative communication method.

OUR VALUES...

- Presumption of Competence
 - We are people with varying disability labels, AND we are often misperceived as being incompetent or less able because we do not speak. We want others to recognize that we are competent people who do make our own decisions about our lives in our own way ~ and we will work together to overcome other people's ideas about what we can and cannot do.
 - All people can be competent communicators. It is lack of opportunity to develop methods of communication; lack of access to quality education, accommodations and supports; and lack of environmental awareness that contributes to perceived incompetence.
- Belief, Respect, Value For Each Person's Communication
 - We want the right to communicate and all forms of communication methods to be accepted and respected.
 - We want funding and policy practices in place to assure all people, regardless of disability, have the support, access to quality education, and equipment to meet their needs.
- Autonomy & Participation
 - We need support and help to clear away the barriers that make it hard or impossible for us to communicate and to actively participate in decision-making and public policy that affects our lives.
 - We want to work collaboratively with other advocates to gain support for the right to communicate.

BRIDGES GIFTS AND GRANTS

In late 2005 we started a special fund, to which our families and friends have given more than \$24,000 in 32 months. We thank everyone for their kind gifts and GSA for administering the Bridges funds. We are doing quite a lot already on our own, but Bridges over Barriers needs funds to realize our bigger dreams. We appeal to other people to help us.

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>