

# BRIDGES OVER BARRIERS

Newsletter 1, Spring 2006

*Welcome by Andrew to our first newsletter!*

**OUR FC GATHERINGS** started in early January 2004 when Tim and Joey travelled *by train* from Toronto to Guelph with Beth and Peter. I was host in my home with my friend Heidi and my parents Gerry and Elizabeth. Since then, we have met in Guelph every two or three months, on average. Our winter dates have often coincided with snowstorms, so we tend to meet between March and November.

By August 2004, there were six of us FC communicators meeting regularly, with our parents and supporters. We come from a wide area--the Greater Toronto area in the east to the greater Detroit area and Petrolia in the west. Sometimes we invite friends to join us, so that there may be 20 or more at our gatherings. Always, we depend on Beth as our mentor and main facilitator. As our numbers have grown, we have taken to meeting at the Ignatius Jesuit Centre of Guelph, where we can use a nice big room for our FC conversations and can go for hikes.

Before each gathering, I send the agenda by email to everyone, with some suggested topics for discussion. At the gathering, there is always time for the FC friends to mention difficulties they may be having in their lives, and to ask advice. Several of our FC friends, attending their first FC gathering, were astounded to realize that other people used FC. They had thought they were quite alone and unique in needing this form of communication. The gatherings are a unique part of their lives and have inspired the vision of Bridges Over Barriers.

For the March 2006 meeting, we decided to invite friends to witness the FC conversations. Two of these friends wrote messages afterwards about their impressions and responses (pages 8-9). During our FC conversations, only the FC users talk. Parents and friends, who are keen to talk about all sorts of helpful topics with one another, save this for the lunch and hike breaks. So the FC users shape the flow of discussion.

## ***What is FC?***

*Facilitated communication is a form of augmentative and alternative communication (AAC) that helps people who cannot speak or who have limited speech to communicate by typing on a keyboard or pointing at letters, images, or other symbols to represent their messages. Through frequent practice and careful support, some FC users can type independently. Facilitated communication has been used as a means to communicate for individuals with severe disabilities, including persons with labels of mental retardation, autism, Down syndrome and other developmental disabilities.*

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**OUR VISION** began with Andrew's dream in July 2005, when he typed: "I want to say that FC is so important that I'm in the mood to start something. I want to start a place of refuge and organization for FC and life planning and autism. I'm thinking about my Autism Project I want to organize. This is really my dream. Here goes. I want to be in a place where I can greet friends, host meetings, teach about FC and other things that help us. For now, it can be based in my home. Later it must be bigger. I have to tell you that this is really my idea. This is so happy-making. First the FC Gathering and then the world.

"We would not necessarily live together, but some of us might like to live closer. We would welcome people who use FC and other communication strategies. It is about building bridges, not walls. I want to share this dream as I think we have become important to each other in a powerful way. I think that our FC gatherings can be made more regular and frequent. We can talk more often online or email. We can teach others. I want to share my dream with you and ask what you think."

This is my poem:

## DEEP FC DREAMING

I am dreaming of a place  
Where we can come together,  
To be together,  
To communicate together.

I am dreaming of a place,  
where I can be a leader and a friend,  
a person who helps  
and a person who needs help.

I want to dream with you, my friend,  
To build that bridge you told me about  
Because we both like bridges.

Dream with me  
And we will make that place I dream of  
And the bridge in your dreams.

*Bridges over Barriers is a centre for friends and family who share the challenges of autism to come together to share support, ideas and community. Bridges 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 of pioneers to include more people. We would like there to be 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.*

*I am really serious about this!*

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## SOME THOUGHTS ON BRIDGES; SOME THOUGHTS ON BARRIERS

*Beth Komito-Gottlieb, Bridges' principal facilitator, has helped everyone in the group.*

For the past two years or so, I have had the opportunity to get together on perhaps eight occasions with six extraordinary people who have become like a select family to me. Andrew, Little John, Big John, Ken, Kevin, and Tim, core members of this group we now call Bridges Over Barriers, come to Guelph with their parents and sometimes siblings, supporters and friends to several gatherings each year where we all relish time together sharing conversation, triumphs, ideas, difficulties and good food.

When we first began to get together, it was--well I guess you could say it was a little on the wild side. It was not as simple and straightforward as arranging a social occasion and just showing up. New places, new faces, unfamiliar voices, unpredictable and unrehearsed situations. But all have become friends, sharing on more levels than most friendships can claim. The core members all use facilitated communication as one means of interacting with others, and they share the label of autism. They have in common challenges that the rest of us are only beginning to get glimpses into and glimmers of understanding. And yet, these men are also all unique individuals.

Andrew is a leader and a visionary. He wants to teach and leave his mark in this world. Tim is spiritual and speaks often from his soul. Little John is soldiering bravely as he masters a new communication device and broadens his ability to speak with this new "voice". Our youngest member, Big John, brings to the group the energy and enthusiasm that comes with being a young adult, and he turns to his older friends at times for advice. Kevin, an author and deep thinker is always willing to offer his thoughts on any subject and readily expresses his concern for the others in the group. Ken is the gentleman, well-mannered, kind and always with a lovely smile to share with the rest of us.

I do not want to sound sappy, nor do I want to understate the sense of awe and triumph I feel when I think of how this group has come together, through love and determination on the parts of the *Bridges* members and their families. Being together was not easy the first few times we met. And even now, at some gatherings, one member or the other may have difficulty staying in the room or getting his words to come out the way he wants. But the more we meet, the easier it seems to get, and now observers are amazed to witness our conversations, often well over an hour at a sitting, two such sessions over the course of a day, with members pounding away on keyboards or poking at their letterboards, listening to each other and responding thoughtfully, with little visible signs of discomfort at being touched or difficulty staying "on task" as people with autism are reported to be. No signs of cognitive impairment here; no difficulty empathizing with others in this group!

This group has built bridges, to each other, to their families, and now to others as they act on the dream of reaching out and broadening the circle. They do not pretend that their lives are not challenging, but in this group, autism is not synonymous with barriers. And whatever barriers they come upon, this group of friends hopes to build more bridges up and over. I think this bridge building is making them stronger. I know it is giving them, and all of us who share it with them, a great deal of joy and satisfaction.

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## WHAT FC MEANS TO ME

*John MD: (Before FC) the door was closed for me to express myself. The room for improvement could be seen. Hard—couldn't communicate. (How FC has changed life) I can communicate to anyone and communicate to Fr, dad and mom. Family was not listening but are now. I am able to speak through the FC to let my life be interesting.*

*Ken: (Before FC) I did not talk and people did not know what I said and thought. I felt sad and frustrated. (How FC has changed life) I feel fine with FC. FC helps me talk well and working at Options. It makes me feel intelligent and makes people know how I feel.*

*Kevin: It's difficult just being autistic. FC marks the difference between hell and life.*

*Andrew: I know what you mean, Kevin. It is a heavenly gift to have FC.*

*John K: What is FC to me? It is my chance to talk to the world. I only get to say my words in this group or in Beth's hands.*

*Tim cautioned: I think the difficulty in finding FC help is people's inability to cope with our volatile nature. People can learn FC, but if they don't learn all our other strange ways, it will be difficult.*

*Andrew explained one of our challenges—"FC is a minefield" means "dangerous ground" and "FC is controversial."*

*John K (on why FC is controversial): I think it is because people with autism are saying things that surprise people and they get worried.*

***FC is my bridge to the world.*** (Andrew, December 2003, July 2005)

*FC is not a cure but a bridge. I am connected to the one I am FCing with and she connects me to others. Before FC, 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. I was sad, angry, frustrated and worried if I needed to say something.*

*I remember the first time I used FC. I remember trusting M-- and letting her show me words, and then I pointed to them and I spoke for the first time in words that made sense. When I learned how to communicate in a new way--when I learned to use FC--I had a whole new world open. I knew I could think and was smart. Now I have a way of communicating and though I am still autistic, life is better.*

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## SHARING STRUGGLES AND STRATEGIES

*Andrew:* My FC friends are a dear part of my life. We have a lot in common. We listen to the struggles, we share, we root for each other. It is the knowing that our bodies are not in our control that makes us like a family--related. I think the struggles are in our bodies, and the strategies are what helps. I might write about impulses and losing it [control]. M-- thinks the impulses are always there, latent, but that we people with autism can hold on most of the time. Other people should know that it is always a struggle, even when there may be no outward sign. We all lose it sometimes in different ways, I guess. I get hyper and run and scream and clap if it is bad. Don't worry if you lose it when we are together. I have to control myself if others lose it. But I don't want them to feel bad.

*Kevin:* [Addiction] is like a demon in my head.

*Tim:* FC has helped a lot but I think the obsessions are still strong,

*John K:* The thing for me is I am not so happy when people say I can't do things my way. [Everyone agreed that others may not like our passion to tidy or rearrange things, especially in the kitchen]. The world needs autistic people to keep it tidy!

*John MD:* I get dizzy when I look at things straight.

*Tim* agreed that looking straight at keyboard is a problem.

*Andrew:* It is because of confusion in my perceptions.

## FOCUSING THOUGHTS

Everyone listened as Beth spoke a word and, after a minute or two, typed their thoughts on:

***CONNECTIONS: what does it mean to you?***

*Ken:* Not being disconnected. Not alone. Not separate.

*Tim:* I think it is a good word for what we are doing and I like it very much. It is good to be connected to people you love and I think you are very connected to me.

*Kevin:* Connection is reassuring and security, and comfort. It was quite an interesting task for Beth to come up with. I like my connections with this group and my family.

*John K:* I feel connected to my family and friends. The world is a blur if we are not connected.

*John MD:* Connections are important. I want more friends. I have a dream to be more and more connected.

*Andrew:*

Connecting is my purpose in life,

It is why we are here.

My world is connecting the dots

You are one dot

I am another

We live in a world of connections

And the lines spread out from here.

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*Several of our men express their thoughts as poems. John MD wrote his poem some time ago, before our group began meeting. At the March 2006 meeting, Kevin remarked: "I would like to write a poem about this group even though I have never written poetry before." Here are four he has sent for this newsletter:*

## Family

Family are special friends  
always there for you  
each with different traits and gifts.  
What one person lacks  
another has.  
When one person is sad  
another cheers him up.  
For every joy  
someone is there  
to share the happiness.  
I will always cherish each one.  
I will have good memories.

## Aidan

Aidan is a cute little boy  
who's always underfoot  
chatting and playing  
and wanting attention.  
Even though he's my nephew  
I sometimes feel jealous  
that he takes up time from me.  
It can be hard being an adult  
and so dependent on others.  
Aidan is more able  
to do some things  
than me.  
He certainly is good  
at making his needs known.

## The Beach By John MD

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.

## My FC Group

When I communicate with my FC group  
I feel like we've always been together  
and that we have a connection  
deeper than family.  
I guess we are in fact  
a type of family  
sharing the common bond  
of silence  
in a world that is seldom silent.

## My House

The guys I live with  
are fun to be around.  
We do many interesting things  
together.  
The staff is great too.  
They have lots of patience  
and good ideas.  
Sometimes I want to be alone  
and that's okay.

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## SOME POEMS BY ANDREW

### *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.

### *Trains* (15 December 2004)

Trains move me in many ways;  
I like to be moving with them.  
My movement problems are Inconsequential,  
because the train speeds along the track,  
in the right direction.  
It feels like the motion  
becomes a part of me  
and I am part of it.  
The sounds calm my nerves  
and I am happy.

### *Spring* (26 March 2003)

What a time it is  
when the light changes  
and the sun comes  
back to us in fullness  
It is a time of beginning again  
and coming outside to see the world again.  
The world is washing itself off  
with the rain  
and soon new things will appear  
growing and showing off for us.

### *Words* (15 September 2004)

Words are our way  
of reaching each other.  
In words I tell my story.  
I say who I am  
and who you are to me.  
My words can sail to you  
or hit their mark like a dart.  
I tell you I love you  
or can complain if I'm hurt.  
I'm grateful I found my way  
to share words,  
very grateful indeed.

### *About Being an FC Poet*

I am learning to be a poet.  
My words begin in my heart  
And go to my head.  
I let them flow on out of my hands,  
with the guiding holding hand  
of my facilitator,  
on to the keyboard,  
and out comes the voice.  
Not my voice,  
but as close as I will get  
to reciting my poems out loud.

### *Anticipation* (January 2006)

I love waiting for you to come:  
In my mind I prepare,  
I plan our time together.  
I feel anticipation,  
wondering how it will be.  
It is love for you  
and all I am with you  
that stirs me to do well.  
Your love and faith inspire me,  
and I love and have faith in you too.  
I dedicate today to you.

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## TALKING THE TALK

*Andrew Foster's story about the Bridges gathering on 25<sup>th</sup> March 2006*

We've become accustomed to using the phrase, "people with autism", as a way of ensuring that we're not using autism as anyone's defining characteristic. At the Bridges over Barriers gathering hosted by Andrew Bloomfield at Ignatius College, Guelph, Ontario on 25<sup>th</sup> March 2006, it seemed to me to take on a rather broader meaning.

Andrew has been hosting small gatherings of young men with autism for some time, but this was the first since the start of the Bridges over Barriers project, so the participants were invited to bring friends and family (not to mention Andrew's service dog, Amy) along to watch a day long session of facilitated communication (FC). Six FC users were there, and about twenty or so people altogether. It was a very informal occasion, this being announced by the fact that Gerry Bloomfield *was not wearing a tie*. That made it even less formal than gardening. The gathering was facilitated by Beth Komito-Gottlieb, an experienced communications specialist who knew many of those present. We hear that autistic people sometimes have difficulty focusing, but I'm not sure that the rest of us were any better that day. Seated at Andrew's right hand, Beth kept the discussion moving, making sure that everyone with something to say was encouraged to say it; always ready to give help when it was needed, and sharing her skills with others.

Autism itself didn't play a big part in the discussions: it was more about the lives of the six people. Since FC was the reason why we could be together that day, it was interesting to see it in action, and then begin to take it for granted as things moved along. We were given some insights that we don't often see. FC clearly isn't easy, and it shouldn't be. It is teamwork, a bit like a dance, and few of us are natural dancers. It took one young man a little time to get into the rhythm of the occasion, but he was soon communicating easily, and I learned afterwards that like Andrew Bloomfield, he is a poet, and a good one, too.

The ages of the group ranged from 19 to 37, but the sense of equality among them was striking. These were mature people who cared for each other and wanted to hear about the events that were shaping their lives. The youngest member of the group was frustrated with the way he was treated at school, and this led into a discussion on ways to improve this. Everything is about communication, so writing is the medium that they agreed would work.

Very early in the meeting I was struck by how outgoing the FC participants were. One was a little quieter at first but got up to speed later, enthusiastically contributing to the discussions. By contrast, the families stepped back to let the participants get on with it, the focus being on the communicators rather than the facilitators and guests.

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To return to my opening words, I wonder if we're using that phrase, "people with autism" properly? It might not be stretching it very far to suggest that after a while, everyone in the room could be described that way. Autism was simply something that was present with us in that room. It didn't belong to anyone; it was simply a barrier that became a little easier to cross with the right people there, working together to construct a bridge over it.

## ***Vera Petkovsky's Letter about the March 25 Meeting***

*It was a privilege to share in your FC gathering on Saturday March 25<sup>th</sup>. I enjoyed the glimpse into the lives of some people with autism, like my friend Ken Moon. I think it's amazing that these men – who cannot rely on speech, facial expressions and gestures, like many of us do – were able to communicate using their FC boards and keyboards. They are individuals, with thoughts and emotions they long to share with family, friends, and others. It must have been very frustrating for them not to have a way to express what was inside them – FC is a tool that gives them a voice.*

*When I first met Ken, on a Sunday afternoon outing with his parents, I was a bit uncomfortable – I didn't know how to communicate with him. When I looked into Ken's eyes, though, I knew there was more to him than his appearance might suggest. The phrase "don't judge a book by its cover" leapt to mind. I had no experience with autism before I met the Moons, but, over time, I have come to understand some of Ken's challenges, as an autistic adult, and those of his family and friends.*

*The Bridges men are adults and they lack the support and resources that are available autistic children and their families. It's encouraging and helpful (and hopeful) to know that they have each other. I pray that this group finds a way to make a difference, not only in the lives of these six men, but for other autistic and developmentally challenged people.*

*It was poignant to see people with a lifetime of suppressed emotions and thoughts being able to speak out and share them through FC. This is a precious gift that others should be allowed to experience. I look forward to future opportunities to develop my friendship with Ken, his friends and their families, at future FC gatherings. I hope I will be able to help them and make a difference in some way, as they are making a difference in the lives of the people who are blessed to know them.*

*Thank you, Elizabeth and Gerry, for bringing Beth into this circle and making a place for these special men to share community and friendship – with each other and with their family and friends. May they continue to grow in their ability to share and inform others through FC. God bless you all.*

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## BULLETIN BOARD

### ***Appeal for Bridges Over Barriers***

We need to make everyone aware that people who do not speak because of movement and communication disorders can be helped to express themselves reliably. FC works for the men in our group, but may not work for all. We need to encourage and train more communication allies who will provide the physical and emotional support that we need. We want family members and friends to feel more confident in facilitating communicators. We want children and teenagers with autism to be able to reach appropriate help. We could organize meetings for people to understand language and speech and to discuss and try out communication aids and systems that can make a real difference. We want people to respect and listen to us as persons who have intelligence and insight. We want to continue meeting in quiet, calm places where we are accepted and understood.

Bridges Over Barriers needs funds to realize our dreams. Guelph Services for the Autistic whose mission is to help adults with autism to have their own homes and to live with dignity and safety in our communities, responded to my appeal to shelter gifts made to Bridges Over Barriers in its early years. GSA directors and my friends have given a total of nearly \$9,000 in the first six months. GSA's Treasurer issues official receipts for gifts. Two professional people, friends of Bridges, are willing to advise GSA on worthy projects. If you can give, please send your cheque made payable to GSA (with Bridges Over Barriers on the memo line) and send to: GSA Treasurer, 16 Caribou Crescent, Guelph, Ontario, N1E 1C9.

Kevin and Gloria in our group have just published a book of great interest. Much of the book is in Kevin's "voice." These are details:

### ***The Road Trip: Life with Autism***

by Gloria Pearson-Vasey and J. Kevin Vasey (Ottawa: Novalis, 2005). ISBN 2-89507-603-0.

### ***Summer 2006 Events of***

***Interest*** show that there is renewed interest in FC. Several of our families plan to take part in one or another. All have features of our dreams for Bridges Over Barriers.

***TASH Teleconferences*** (each 90 minutes long) on issues related to Facilitated Communication, co-sponsored by The Autism National Committee, from May 17 to June 5. Check <http://www.tash.org/teleconferences/>

Autism Network International presents ***AUTREAT 2006***, June 26-30, 2005, a retreat-style conference run by autistic people, for autistic people and our

friends and families. It is an opportunity for autistic people and those with related developmental differences, our friends and supporters to come together, discover and explore autistic connections, and develop advocacy skills, all in an autistic-friendly environment. This year it is at a Philadelphia-area college campus. Two of our families have expressed interest. Experience of such a autism retreat could help our Bridges group plan something like this in Ontario. Check <http://www.ani.ac>

The ***Facilitated Communication Institute*** at Syracuse University will be hosting a ***weeklong summer institute*** July 17-21, with conference sessions and hands-on workshops aimed at both new and veteran FC users and facilitators. It's possible to attend all week or for just one day or one session (fees are pro-rated). Check <http://suedweb.syr.edu/thehci/Summerinstitute2006.htm>