

## BRIDGES-OVER-BARRIERS

### 2009 WILL BE A GOOD YEAR FOR BRIDGES!

The communication support group we now call Bridges-Over-Barriers has been meeting since January 2004. It has been sheltered by Guelph Services for the Autistic since November 2005. Communicators in the group, discovering others who also use supported typing to “speak”, have been able to trust one another to share thoughts, fears and dreams. They have learned from one another’s lives, that they are accepted and respected, that they have rights to know about options and to make real choices. Bridges members help one another to face changes and challenges.

#### MY GOOD LIFE

I like the barn.

I like the horses and the sheep.

I like coming here every day and

I like seeing the cats in the window  
looking at us.

I like eating here very much.

The food is good

and the company is great.

I think I will live all my life in the country,

So I can be a happy man all my life.

-KM, 20 February 2009

Friends and family have been generous in supporting the Bridges dream. “Supported typing” is far from easy for communicators and their assistants, and the business of organizing and travelling to Bridges gatherings is physically and emotionally draining. But the value of Bridges as forum and support group makes everything worthwhile.

Bridges members have been able to move on in their lives. By expressing what matters most to them, they convince their family and friends to

help them to make their lives better, even to realize their dreams. Sometimes this means moving away, too far for some to meet in the Guelph gatherings. So strong are the ties of friendship woven in Bridges gatherings that we can remain friends and Bridges will help us to keep in touch.

Members of Bridges and GSA as trustee and sponsor are committed to the goals of helping more people to be communicators and communication assistants and to proclaiming the rights of everyone to have more choices and control over their lives. Three projects in 2009 should further this goal. One is the production of a Bridges video to illustrate supported decision-making and Bridges as a support group. A second is the development of the Bridges Tech system that will make Bridges gatherings smoother and allow virtual gatherings over the Internet. A third is the production of a Bridges manual explaining the theory and practice of supported typing. We may also host an event in the fall of 2009, to launch all these resources. Our next newsletter will tell more.

#### HOW TO REACH US

Postmail: Bridges-Over-Barriers, 16 Caribou Cr, Guelph, ON

N1E 1C9. Please make donations payable to GSA, with

“Bridges “ on the subject line. Tax receipts are issued.

Send email to [ABC\\_andrew@hotmail.com](mailto:ABC_andrew@hotmail.com) (Subject: Bridges).

Visit the Bridges webpage at: <http://www.ont-autism.uoguelph.ca/bridges.shtml>

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## BRIDGES-OVER-BARRIERS

### WHAT WE SAID AT RECENT BRIDGES GATHERINGS

(15 November 2008, 21 March 2009, 25 April 2009)

#### ***What is important about individualized funding? How could it help me to build a good life?***

AB: I guess it means decisions are made about what's best for me and not for some group. It means my life is a good fit for me, not for some idea about someone autistic. We can get away from stereotypes.

KM: It is important to have money to live on. We need money to pay the rent and money to pay the workers to help us in the community. With IF, I will be able to do work I like. I would work at David's farm every day instead of going to the city to do boring things.

TM: Very important. I can be independent and make choices about who we are with and where we live.

RA: I like to do my own grocery shopping.

MM: I would like to say that funding is good.

AB: I want everyone to have IF.

#### ***What helps me to be included in discussions with others?***

JMD: Hearing helps me to be included.

RA: I enjoy talking with others who share my interests—such as TV shows. I look up Google to find out more.

TM: It helps me to have a facilitator to help me and explain what is to happen.

KM: I come to my circle meetings and I tell them what I want to do.

AB: I find it helpful if I am included because I know I am valued. Ask opinion. Communicate my way. Respect me and listen to me. I need help to answer, not to understand. What bothers me is that if I use FC, I am not always believed. I know I need to try harder to be independent.

#### ***What does independent planning and facilitation mean to me?***

JMD: Living like other people.

TM: It means that I am in charge of my life and I can be with people I like.

KM: I think it means that the plans are about my life and what I want to do.

RA: I would like to live with my brother.

AB: Beth is my facilitator for communication—my helper to get what I want to say. Funds that help me to plan my life. I want to say that it is essential to hear my voice. No decisions are made about me without me.

#### ***Individualized Funding***

*(AB, May 2005)*

I like to be a pioneer  
but it is too slow and scary sometimes.  
I have lots of good people in my life.  
My Aroha and GSA will go on  
supporting me after my parents die.

I think IF has made  
all the difference for me.

I might tell people  
that it is essential to get IF,  
because it is the only way  
to give people choices and options.

We must have the freedom  
to have our own life,  
choose our own path,  
choose our own supports.

I think we need to know  
we can provide  
for our own supporters,  
so we can choose good ones.

## BRIDGES-OVER-BARRIERS

### ***Who does the planning in my life?***

JMD: Mom and Dad

MM: I do.

KM: I do the planning with help from others.

TM: I do but with your help.

RA: I do with Mom and Dad's help.

AB: I do it with help from my Aroha FAB group. I am on FAB so we all do it.

### ***Who should look after spending and accounting for the funds ?***

JMD: Dad!

KM: My Dad looks after funding and paying the bills.

TM: It should be me with help from others.

AB: My closest friends and family with my voice. I like it this way. An agency is not needed. As long as people control the choices about their lives, they can have help looking after the accounts.

### ***What can a professional facilitator do to help me with planning my life?***

KM: They can listen to me and talk to me about what I want to do. PDI talks to agencies on my behalf. I appreciate all the time he spends in talking for me.

AB: I hope facilitators like JL and JM could help my friends whose lives are not yet the way they want them to be.

MM: Yes, but I want to know I can trust them.

RA: I should look after the money.

TM: I think it could help, but don't think someone outside will help as much as you and Dad.

### ***How can support groups like Bridges help us in planning and creating good lives?***

TM: Bridges friends help me by being here to meet and talk. It is very important to get our

words out. I am glad we can communicate in the new way. This is a great bunch of people and I worry about how to communicate when we leave.

KM: Friends accept us the way we are and help us to do our best. I like the Bridges men very much and we need to support each other when we are hurt and when we are happy. I want to be happy and kind all the time with people who don't know us very well. I want the movie to show us men talking to each other, and to tell people we are smart and finish what we started to do. I listen to the other men telling me what they are doing and I tell them what I am doing.

Sometime I like the things the other men are saying. Kevin Vasey shared that he was getting a dog and I thought I would like a dog too.

MM: Friends can help us. Friends are the reason why I can FC today. We are smart and good friends.

JMD: This is my group of friends. Bridges means great friends who help in hard times.

KV: Communicating with people who like me and understand my heart and soul is critical. This is a unique opportunity to discuss all our thoughts and solutions. We often talk about things of universal importance.

RA: I get to know other people.

AB: I think that Bridges has made a big difference in my life. My friends know my language. Being a support to each other and providing a place to talk things through and work out the ideas together. Bridges means the world to me that we have got close with binding ties. I like it that we are calmer and support each other. It shows that we can care about others, have empathy, and let others touch us. I think we need to talk with other supporters, not only our parents. My feeling is that I don't know what I would do without our Bridges friends.

## BRIDGES-OVER-BARRIERS

### ***What does Friendship Mean?***

Tim and his parents Betty and Mike will be leaving soon for their new home in Antigonish, Nova Scotia. We will miss their presence and insights at our gatherings. But having shared so much, we will always be aware of each other.

Betty found these words of the poet Khalil Gibran about true friendship

*Your friend is your needs answered.*

*He is your field which you sow with love and reap with thanksgiving.*

*And he is your board and your fireside.*

*For you come to him with your hunger, and you seek him for peace.*

*When your friend speaks his mind you fear not the "nay" in your own mind, nor do you withhold the "ay."*

*And when he is silent your heart ceases not to listen to his heart;*

*For without words, in friendship, all thoughts, all desires, all expectations are born and shared, with joy that is unacclaimed.*

*When you part from your friend, you grieve not;*

*For that which you love most in him may be clearer in his absence, as the mountain to the climber is clearer from the plain.*

*And let there be no purpose in friendship save the deepening of the spirit.*

### ***How are our moods and state of mind related to our health and the ways our brains work?***

#### **MY GOOD HEALTH**

I am enjoying good health these days.

My health is always on my mind;

My mind is always effected by my health.

In my mind, health and mind are like cause and effect.

I do not know where one begins and one ends, but it feels like sunshine to my brain cells,

when it is all working in harmony.

I hope it will last--this breathing space of good health

It is my chance to be with others

in a place of balance and strength.

-AB, 4 March 2009

Andrew asked for everyone's thoughts about how our brains and bodies, health and moods are interrelated.

TM: Mind and brain are closely related.

KV: When I am in a bad mood. I feel tired and sick and worried about everything.

KM: Having autism is always being run by your brain not always working, but what I eat makes a difference. My need is for others to tell me what I can eat.

KV: I definitely feel better when I follow my diet.

MM: Yes because I am real to myself.

TM: Diet makes a difference but it is a pain and I don't like it.

### ***When we feel ourselves slipping into ill-health and bad moods, can we do anything to stop or prevent them?***

KM: I am not aware, but if you tell me, I know. You teach me to sit on my hands.

TM: I don't know what to do when I feel it and need help to pull out of it. It helps if you and Dad are good to me and don't get mad at me, so I gradually climb out of it.

KV: Sometimes I can stop if the occasion calls for making a good impression, such as planning for my future and my dog. At meetings I can do it, and collapse later.

AB: I feel excess energy and sometimes it escapes when I am tired and not able to control myself. I need outlets. It really helps me to "listen to my body." I can have short naps and rests.

## BRIDGES-OVER-BARRIERS

### CREATIVE STRATEGIES & ACCOMMODATIONS

TO HELP PEOPLE WITH AUTISM AND OTHER NEUROLOGICAL CHALLENGES TO GROW IN LEARNING, COMMUNICATING, PARTICIPATING AND RELATIONSHIPS.

*Several of our Bridges circle were among the 90 attending the London workshop led by Martha Leary on 22 April 2009--Jim and Gloria Vasey from Petrolia, Matt and Jacque from Toronto, and Lea Tran of Guelph, Andrew's friend who introduced Bridges members to Horticultural Therapy in 2008.*

*This topic is very relevant to our people who live with such severe neurological changes that they cannot use their voices and need special strategies to express their thoughts reliably. So in this issue we present two reports on the workshop. One is by the Vaseys who have lived with Autism for nearly 40 years and the other by Lea, for whom Autism Spectrum Disorders are fairly new.*

#### **The Vaseys' Report**

*The Vaseys had not met Martha since the mid-1970s, when three Bridges members--Kevin, Tim and Andrew--shared a cabin at Camp Towhee in a summer school organized by what became The Geneva Centre. Martha was the SLP in charge of the program.*

Martha recalls thinking she knew about autism until 1991 when she learned how sensory and movement differences affect a person's participation. She continues to learn so much from people with autism. She noted that autistic people want to discover their own competencies. They may not be well served by current funding priorities. Official definitions of autism does not mention sensory or movement difficulties, which can affect all aspects of living including emotions, thinking and feeling as well as communication.

Repetitive behaviours by people with autism are regarded less tolerantly than behaviours of "normal" people to relieve stress—such as tapping on glass or chewing a pencil. We would usually help rather than criticize someone with seizures or Parkinson's. But most assume that autistic behaviour such as rocking the body or flapping hands is stereotypical, intentional, disruptive and not functional. We tend to say: "Stop that!" or "Put your hands down!"

Martha's key message: Autistic people are not broken! They do not need to be "fixed." Autistic behaviours are not a choice but part of their neurological condition. The label Autism is more about what we feel than about an autistic person's self-image. We must examine our assumptions and provide appropriate supports.

Flexibility is provided by reliable sensory information in all of us. We have lots of options and different motor patterns adapted to various conditions. We make continuous body adjustments for circulation and other functions.

Autistic persons have fluctuations in their kinaesthetic or body sense. They learn with great difficulty and lots of repetition. They experience delays and variations in speed and accuracy. When a question is repeated if they are slow to respond they must go back to the beginning and reorganize.

## BRIDGES-OVER-BARRIERS

CREATIVE STRATEGIES & ACCOMMODATIONS,  
continued.....

Sensory difficulties reported by autistic people:

- Background noise and sudden noise
- Loss of feedback
- Touch does not fade
- Lighting can be painful
- Foods may not give enough feedback.

Movement and sensory differences may cause  
difficulties with:

- Starting
- Stopping
- Executing
- Continuing
- Combining
- Switching

These difficulties affect:

- Postures
- Actions
- Speech
- Thoughts
- Perceptions
- Emotions

Paradoxes:

- People with Tourette's, Parkinson's, Autism and Catatonia can do things sometimes but not always
- An increase in emotion causes an increase in unusual movements for vulnerable and fragile people
- The more attention paid to a behaviour, the more difficult to inhibit it
- Focusing on performance can cause rapid fatigue.

Implications

- Behaviours may not be what they seem
- Behaviours may be hard to inhibit
- A history of difficulties can make future difficulties more likely
- Non-responding (freezing, getting stuck) can be due to akinesia
- Severe over-reactions may be due to hyper-sensitivities and movement difficulties
- Self-esteem is improved by asking people what can help with a particular behaviour

Learning to Interpret Symptoms:

- Symptoms have meaning. Example: Tito spins to get rid of blackness (bad thoughts), then spins in the opposite direction to get blue (harmony); this also keeps his body from "fragmenting."
- Symptoms and behaviours are not volitional or intended.
- People have sensory sensitivities that we can't see: sounds can be physically painful and cause nausea.
- Autistics can't watch facial movements and listen to words at the same time: looking away may actually help them to pay attention better.

Autistics sometimes cannot find the emotions that they want at any given time. Often they are not able to show emotion. Their faces may not move appropriately. Their differences in feeling and sensitivity in the mouth area affect chewing, swallowing, saliva, speech and facial expressions. They may come to rely more on smell and be able to identify people most reliably through scent.

## BRIDGES-OVER-BARRIERS

CREATIVE STRATEGIES & ACCOMMODATIONS, continued.....

- It's critical to recognize the possible function of a behaviour, and that the autistic person's experience of the world may be different from ours. Routines and rituals are ways to suppress or self-control other behaviours.
- Each person is different in movement and sensory difficulties and in the accommodations that work for her or him. It's a good idea to make a video to train support workers.

### Helpful Supports and Accommodations

#### Guiding Assumptions:

- Communicate
- Respond
- Adjust
- Agree

It's not about performance; it's not about control: it is about "power with" and "Together we're better."

#### Properties of Supportive Relationships

- Trust
- Intimate connection
- Shared vision of independence
- Presumption of competence
- Understanding
- Inclusion'
- Respect for neurodiversity
- Collaboration

Rhythm is a powerful form of accommodation. A supporter can help by getting into the rhythm of a person with autism. We walk and talk to rhythm. The environment has rhythms which may be comfortable or not. Relationships are

based on rhythm. People with autism put their rhythm out there so others can see it. By adjusting to the rhythm, a supporter or friend can develop a relationship. See Oliver Sacks's book about *Musicophilia*. Autistics can apparently sing to karaoke even when they cannot speak. People can share emotions by dancing. The movie "Parkinson's and Music Therapy" illustrates the power of music with people who cannot move. Music soothes and comforts. Rhythm helps to regulate someone who is stuck, when it's impossible to push or pull him.

### **Lea's Report**

I learned a lot at this workshop and am thankful that I got the opportunity to go. I could also chat with Martha before things got started—about her experience as an urban farmer in Halifax and my role with the Guelph Enabling Garden.

Here are some important points I learned:

- When speaking about sensory and movement, we could be referring to physical movement, thinking, speaking, feeling, and perceiving.
- Our definition of "normal" is very narrow.
- Whenever we feel that we are being judged, we are more likely to feel stressed. This stress can come in the form of repetitive behaviour. For instance, a lot of people in the room were nervously tapping their feet or playing with their pens. So this repetitive movement does have a function. It's happening for a reason.

CREATIVE STRATEGIES & ACCOMMODATIONS, continued.....

## BRIDGES-OVER-BARRIERS

The participants of the workshop were then asked to pair up and to tell their partner what was most important to them, but without using or sounding the letter 'n'. I found this exercise to be very difficult. It took me longer to find words that did not contain the letter 'n'. I felt limited and felt that I was being scrutinized.

Martha reported a study that found children with autism took an average of 14 seconds to answer an unrepeated question. In one case, it took up to 28 seconds. I learned that for some people, it might take a while to formulate and communicate an answer. Repeating a question might not help, as doing this interrupts current thoughts and the person being asked the question has to start again from square 1. It might be better just to be patient and wait.

Martha explained that people with autism might have difficulties with: starting, stopping, executing, combining, and switching actions. Sometimes it is necessary to concentrate on just one activity. This affects postures, actions, speech, thoughts, perceptions, and emotions.

We talked about sensory differences and their implications. For example, those having differences in feeling and sensitivity in the mouth might have challenges chewing and swallowing food and saliva. Other implications might include challenges with speech/facial expression. Another example is identification of people through scent due to increased reliance on smell.

Martha showed various YouTube videos during the presentation. We viewed one called 'Peter

Shops'. Peter and his mother took us on a trip to the supermarket. During that time, Peter's mother would wait quietly, apply gentle touches to move Peter on, speak gently, minimize verbal instruction and maximize high-quality conversation.

Martha told a story about a student she worked with who needed to maintain a certain rhythm in his movements. If this student was walking at his own pace and rhythm and a friend was passing him, walking in the opposite direction, a 'hello, who are you?' question would cause the student to stop and bang his head against the wall. Later it was discovered that it would be helpful if friends could take the time to walk beside the student, with the same rhythm and pace while conversing. This way, the student's rhythm would not be interrupted, and he wouldn't have to stop and accommodate. Martha touched on some paradoxes that were interesting:

- A person may manage movements sometimes, but not at other times.
- Increase in emotion can cause increase in unusual movements.
- The more attention others give to what is seen as an undesirable behaviour, the more difficult it might be to inhibit it.
- Focusing too much on performance can cause rapid fatigue.
- Though some movement can be suppressed for a time, eventually it has to be released (as it is some form of energy).

CREATIVE STRATEGIES & ACCOMMODATIONS, continued.....

## BRIDGES-OVER-BARRIERS

AB was quoted, at the Bridges meeting in September 2008:

*I will say No in many ways.*

*So keep trying in many ways.*

*Don't give up till you try many ways*

Martha explained that it is better not to force movements on people. A common mistake of most people is to assume that behaviours that people have developed as accommodations to their sensory differences are meaningless, when the unusual movements have real functions. The accommodation is often not volitional, but an impulse that is not a choice. People with sound sensitivities can often feel the sound in their bodies. Some sounds can affect people so much that they feel nauseous.

“Nancy” who identified herself as being autistic had a lot of interesting things to say. She said that sometimes the volume of her voice is controlled by her emotions. When she has something to say, she just says it. It might come out loud and it upsets people. She doesn't understand why people look so upset but can tell that something is wrong by the expression on their face.

In all relationships, these are important:

- Trust
- Intimate connection
- Shared vision of independence
- The presumption of competence
- Understanding
- Communication

We need:

- Effective supports
- Inclusion
- Respect for neurodiversity

When working together, patience is very important. Nancy said something interesting to add to this point. She said that people will be patient and wait for their computers to process information and to download things to get their questions answered, so why can't they be patient with human beings?

Another important thing to remember is to celebrate people's competencies.

***I dream of Bridges-Over-Barrriers as***  
*“a centre for friends and family who live with 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.”*  
 - AB, 19 October 2005

## BRIDGES-OVER-BARRIERS

### MY ESSENTIAL PERSONALITY AND WHAT MAKES ME THE PERSON I AM?

*-By Kevin Vasey © 23 April 2009*

I am a very sensitive person who tries continuously to deal with a world full of overwhelming smells and sights and noise. I have to work hard to sort out the things that are important at any given moment.

When I watch TV I usually focus on the sound and tune out the visual. If there is something I should look at, I take a quick glance. I occasionally watch an entire program but then I am focused on the picture and the captions at the bottom of the screen more than on the sound.

This sensitivity extends to the environment in general and to societal situations and world events. I feel deep compassion for all the suffering people in the world. Sometimes when I watch the news, I become upset, but I want others to understand that, despite my erratic actions, I must keep informed of worldly events. Even when I am agitated, I do not want to be removed from what is happening in my immediate world or in the greater one.

People need to understand that I must deal with my feelings in my own way. They can help me become calmer by reminding me to relax and breathe slowly. Discussing the situation is especially helpful. The world has always had suffering and I have the ability to advocate for social justice and change.

I am the person I am because of my faith in God and because of the life I have led. Some of it has been very painful, but through it all many people have been there for me. My parents have always been the greatest influence on my life. They are always there for me to see that I am having the best life possible.

Being sent away to residential school was a lonely and frightening experience. At the time, I thought that it was so my family would have more time for my brothers. Now I realize that it was because of my behaviours. I love my brothers and am happy that I have them and their families in my life.

At school, I was considered mentally challenged and so my education there was minimal. Fortunately, I had tutors after school to provide me with basic skills. Also, the final year or two of high school was wonderful because I was using supported typing and able to study meaningful subjects. I was finally treated with respect and recognized for my intelligence.

When I first went to live at a group home, it was like being sent away to residential school again. However, I learned to accept it as a second home because I saw my family frequently and traveled and camped with them. During one wonderful year, I audited classes at St Peter's Seminary with my mother.

All of these life experiences have contributed to my character development as well as to my insecurities and anxieties. I consider myself a thoughtful, spiritual man with a good sense of humour. I enjoy peace, serenity and my own space. I find fulfillment in writing, art, nature and traveling with my family.