

BRIDGES OVER BARRIERS

Newsletter 2, Autumn 2006

communication bridges

bridges connect people
so does communication

bridges need a basis
so does communication

bridges have to be built
so does communication

bridges collapse
so does communication

bridges overcome obstacles
so does communication

bridges cross borders
so does communication

bridges shorten journeys
so does communication

bridges are simple
so is communication

bridges are complex
so is communication

bridges are unique
so is communication

bridges recall the past
so does communication

bridges lead to something new
so does communication

bridges make friends
so does communication

bridges are part of everyday life
so is communication

bridges I like very much
communication too!

Katherin Lemler/Nicol van der Meulen, Sept 2005

Flyer from the last ISAAC conference:

**"promoting the best possible communication for people
with complex communication needs"**

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Not Too Late

*Before I went to the summer institute
at Syracuse University,
I was excited and full of hope.*

*When I got there, I was happy to see
dozens of people just like me
being accepted,
recognized as important human beings.*

*Still I was frightened
that nothing important would come of
this.*

*I had been disappointed
so many times.*

*They showed me it was
not too late
to learn new things.*

*Not too late
to learn to talk
even though am now a man.*

*Not too late
to learn to type
independently.*

*Soon I will have a new computer,
small and with a voice,
to take with me everywhere.*

*I will talk with staff, family and friends
and people in the community.*

*When I become an independent typer,
others who don't speak
will be encouraged to find a voice.*

By Kevin Vasey, a member of Bridges, about his
visit to the FC Institute at Syracuse this past
summer. Kevin and his mother Gloria co-

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BUILDING BRIDGES

Martha Leary, MA, CCC, SLP is a Speech Pathologist and Communication Consultant with an international reputation and practice, as a presenter at workshops and conferences, and as an author. Now based in Nova Scotia, she lived for many years in Toronto where she was with The Geneva Centre for Autism. Known simply as “Martha” to many of us, she introduced several of our Bridges men to communication in various modes, and to FC in the 1990s. A good friend of Bridges and has known Tim, Andrew and Kevin for more than 30 years.

When we asked her to write a piece for the Bridges Over Barriers newsletter, Martha suggested that this could be based on emailed interviews with our group. She asked questions, to which our men replied on August 6. They asked Martha some further questions. We present the transcript of this exchange of ideas. Martha’s term “movement and sensory differences” includes what our men call being “stuck” and “hyper—unable to stop”.

Martha asked: Are there times when you want to do something for yourself and you have difficulty getting started? What kinds of situations cause the most difficulty for you in getting started? What do you feel like when this happens?

Kevin: I feel that being stuck is the worst part of being autistic and it’s what stops me from having a normal life. All the time. Getting dressed. So frustrating. People like Joel say I’m lazy because they do not understand. I get angry and want to lash out but I’ve learned to be patient and keep it inside.

John K: I do sometimes [intend something] in my head and my body doesn’t. It happens all the time. I have difficulty at my school. I get stuck if I am not familiar with it. Like if the teacher changes the order of things. I feel like an angry bull who cannot get started.

Ken: I have difficulty getting started when I want to stand up or sit down or want to eat food. I feel stuck and frustrated when I try to do things and I want help to get started and to finish my action.

John M-D: Yes I really get stuck sometimes. Undress, going to bathroom, to bed. Feel depressed.

Andrew: Our lives are challenged by not controlling our movements. Being stuck in our bodies. I know about being stuck. In June and July, I was more stuck than for a long time. I feel like I could explode. I do feel that my body is not in sync. I am just wired. It feels like I am not in control of my body, so my mind is telling me one thing and I do something else. I cannot participate in life.

When I want to do something and am stuck, I feel helpless and sad but sort of resigned.

It is not the kind of situation for me. It is how my body is at the time. When stuck, I usually show it by my hands clasped over my ears—if I am stuck and my ears are hurting. I feel pain in my ears because it is emotionally taxing. Holding my hands over my ears gives me a feeling of control and some comfort.

Break in rhythm makes me forget what I’m doing [e.g., obstacle such as vehicle on sidewalk, even postman doing his rounds] I think when I am stuck I cannot bear to get much information from others. It is internal. I have to cope with my body freezing, so I cannot take more stimuli.

Martha asked: What helps you to move when you feel like this?

John K: It helps if I think about what it is that I want to do and then I do it. [Picture yourself doing it?] Yes.

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John M-D: I think I need a real polite push. Like when David stood behind me and held my hands, then I could push the wheelbarrow at the farm.

Ken: I need help from Mom and Dad when I'm stuck. Yes, touch helps. And counting too. And I like talking from support people [but softly and not repeated]

Kevin: Of course yelling at me is not the answer. I think we need sufficient time. Sometimes words are best. Other times a touch helps. [Counting?] Yes, my mom does it all the time. A soft firm touch done with kindness.

Ken: I can be helped with a soft touch too.

John K: Counting annoys me [an impatient testing tone is different from a supportive one]

Andrew: Get me to visualize. Someone should say: "Imagine you are doing the activity, not thinking about being stuck or moving." Bouncing and rocking can get me out of a stuck place.

How can other people recognize your difficulty and provide the assistance you need?

Kevin: They should know that I am not being difficult. I am not a child. They should ask me and make sure I know what they want. When I say yes, they should be more patient.

Ken: They can tell by my blank stare. I think they can ask if I'm stuck and I will tell them if I am stuck.

John M-D: Here [FC gathering] freedom from very great hassle. I need a person who FCs to understand me.

John K: [People think you're being stubborn and non-compliant?] I think that they do not understand. I think it helps me if they are kind to me. It also helps if they are a good friend.

Kevin: Maybe John is saying he doesn't like being bugged when he knows what to do.

Andrew: When I am stuck, I am helped to move and do my action if E lightly touches my elbow or the small of my back. Or she may sign. Then just wait a few seconds, and I will do it. That is better than telling me what to do when I know it. Someone can facilitate our movements when we are stuck, like facilitating our communication. When this happens I want people to try to help unless I stop them. If I stay, it is a sign that I don't want to quit. Today I am stuck and I notice that Beth keeps handing me a magazine and then takes my typing hand while it is away from my ear. This is smart. I need my friends to keep trying and to think of smart ways to help me keep going.

Question: We have times of being "hyper", restless, always in motion, unable to stop our movements. Does everyone have these impulses? How do we cope?

In January 2003, Andrew wrote this poem:

What it's like to be me

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.

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*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.*

Andrew: I'm still a bundle of sensations. I feel like I have to keep moving.

Tim: I feel like that all the time. I do not know what to do when I am like that and I do not think I can stop. I try to stop. I am not stopped. It helps to be calm and not get angry with me and not to put me down. People kind and calm.

Ken: I am always in motion because I feel restless and can't stop moving because I feel movement inside my body and I don't know what to do about it. You can stop me by holding me still and getting me to think about something else instead of moving about all the time.

John MD: All the time. You [Anne] help.

Kevin: Of course it is the worst part of being autistic. I am affected by other people's moods. I like calm sounds like in the woods. [How is the atmosphere here?] Quite good.

John K: I hate it. It is the worst thing in my life. My dad helps me in those times. He is kind to me in those times and every day. Swings help sometimes.

Question: What happens if someone tries to stop us when we are hyper?

Andrew: I think that I just go right through them if they get in my way. [Because you cannot stop?] It is because I have to do it ...

Kevin: I am not stopped. I need a reminder. We try to look normal but need help. [What kind of reminder?] Saying "hands" [a cue rather than a lecture]

John K: I think it's extra bad because I start to get mad and defend myself in school.

John MD: I feel mad. Yes, hold hand.

Question: Touching: does it help when stuck or restless? Is touch better than voice?

Tim: I think it would.

Kevin: Touch is good if it is gentle and friendly. If it is pushy I would rather have an angry voice.

MARTHA'S THOUGHTS ON BUILDING BRIDGES

The Bridges group asked Martha some questions about sensory and movement differences and the connections with communication. Here are her answers:

John K: I think we should tell Martha that we are smart people.

You have a good point John. I find that when people move differently and organize their actions and

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communication in unique, sometimes unconventional ways, other people are often puzzled. If a person does not respond in expected ways, some people assume the person has a general incompetence. Often this results in further isolation for the person and fewer opportunities for meaningful social relationships, appropriate education or employment.

Kevin: I hope Martha can come up with some pointers for us.

Kevin, I am learning more every day. I am learning from the experiences of people like you. I do not have adequate answers to explain people's experiences. I have spent time gathering people's stories and sharing them. I hope to help people to begin to understand the concept that sensory and movement differences can mask people's competencies. I recently co-wrote a chapter for a book. I think the chapter is helpful in introducing a labeled person's point of view on sensory and movement differences. Here is the information on the chapter:

Donnellan, A., Leary, M. & Patterson Robledo, J. (2006). I can't get started: Stress and the role of movement differences in people with autism. In M.G. Baron, J. Groden, G. Groden & L. Lipsitt (Eds.), *Stress and Coping in Autism*. New York: Oxford University Press.

Andrew: Martha, why do we get stuck? What is not working right in our brains?

We have been talking about how I am stuck only sometimes and wonder if you have any idea why I have such extreme degrees from fluid to stuck. Why does it happen some times and not others? I can have a week of perfect days when everything is in balance, a week or more of being hyper and restless, a week or more of being stuck and frozen. People who understand can help me to cope with the hard times, but they can't turn a stuck or hyper day into a perfect one.

Andrew, you ask a very good question about what is causing you to get stuck. I do not have an answer. I can tell you that your description of the extremes of fluid and stuck is much like the experiences of other people with movement differences.

Below are a few paragraphs from the chapter referred to above. These may give you an idea of what I mean when I use the term movement difference. If anyone wants the references, I will send them. In the future, I would like to share with you some of the things I am learning about how people are able to 'accommodate' to some of their sensory and movement differences.

What is a movement difference? From: Donnellan, A., Leary, M. & Patterson Robledo, J. (2006), pages 207-208.

Leary, Hill, and Donnellan (1999) have defined a movement difference as "a difference, interference or shift in the efficient, effective use of movement. It is a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion and/or memory." Typically, the word "movement" refers to observable actions, such as posture, muscle tone, head and eye movements, facial expression, vocalization, speech, whole body movements, reaching, gesturing, running, and walking. Our use of the word movement is consistent with research that considers internal mental processes of sensory perceptions (touch,

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taste, smell, vision, hearing, and proprioception), language, thoughts, and emotions as aspects of human movement.

There is a unity of perception, action, emotion, and thought reflected in the writings of many authors interested in movement. The physicist, martial artist, and movement innovator, Moshe Feldenkrais, wrote: "Our self-image consists of four components that are involved in every action: movement, sensation, feeling and thought" (Feldenkrais, 1972, p.10). In his fascinating book, Awakenings, Oliver Sacks (1990) wrote of the experiences of his patients with post-encephalitic Parkinson's disease. The diagnosis was movement disorder. The variety of manifestations of symptoms encompassed many hidden aspects of human experience including these difficulties: perception of the passing of time; interest in normal activities; fatigue; memory; and recurring thoughts. Esther Thelen, a Developmental Psychologist, has researched and described movement in relation to child development. In her view, perceptions, movement, thoughts, and emotions can be linked together by having coincidentally (and possibly routinely) co-occurred. Experience may selectively reinforce them as a bundle. They can be unbundled or softly assembled as required by the context. The individual is always operating within an environment or context and, as the context changes, systems scan, adjust, and shift as necessary to meet new demands. These contextual shifts play a vital role in movement. Context changes come together in such a way as to allow the movement to emerge; the movement and, indeed the person, are part of the context.

No one component is causal in determining the movement because all components and context determine the product (Thelen, 1994). Thelen further explains:

...even behaviors that look wired in or program-driven can be seen as dynamically emergent: behavior is assembled by the nature of the task, and opportunistically recruits the necessary and available organic components (which themselves have dynamic histories) and environmental support. (Thelen & Smith, 1994, p. 73).

An example is easily seen in the use of speech. Speech is not lost or gained; rather it emerges when all components and context, appropriately regulated and organized, allow its production. For many persons, autistic or not, stress makes speech difficult and even impossible at times. Paradoxically, for some people with movement differences, stress can help produce speech. The late Arthur Shawlow, Nobel Laureate and father of an adult son with autism, reported that his son could say a complete, and original, context appropriate sentence about once every eight to ten years. He asked an audience at the Autism Society of America conference how many parents had similar experiences and about 15 sets of parents raised their hands. They met for awhile and compared notes. Most of the labeled children of these individuals were able to speak under extreme, often negative, circumstances. Some had only spoken once or twice in a lifetime (A. Shawlow, personal communication, July, 1996).

Andrew: Please Martha, what is the connection between being unable to move sometimes and not being able to speak with our voices?

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Speaking is the result of some very complex cooperation among various systems of the body. Sensory and movement differences may affect each person differently. For many people with autism, any use of the voice is challenging, others may use the words that others have said (echolalia), but experience difficulties generating spontaneous speech. Temple Grandin, a person with autism who is quite able to speak, describes some of her speech challenges in the film, *A is for Autism*: “I cannot follow the rhythmic give and take of conversation. People have told me that I often interrupt and I still have difficulty determining where the pauses are.”

Consider the body systems involved in speaking: free movement of the jaw; agility of the tongue; well coordinated, effective breath control; moving at the right time; coordinating the movements of these different systems; using facial expressions and gestures that match the meaning of what is said; using the vocal mechanism – ‘voice box’ or vocal folds – with the right amount of force and pitch; keeping the rhythm of a conversation by taking a turn after your partner speaks, and so on. When sensory feedback and reliable movement are compromised, any of these systems can be affected.

In the literature on movement ‘disturbances’, there is frequent reference to ‘muteness’ as a symptom. This can happen to people with Parkinson’s Disease or classical Catatonia, as well as to people labeled with autism. For some, muteness is temporary or intermittent. For others, muteness is a constant in their lives. The actual mechanisms that cause this type of muteness have not been identified.

Andrew: Please Martha, can you explain why I and others can do routine things when we are a bit stuck, but when it comes to communication, we have to be supported? By support, I mean having physical and emotional support.

People with autism have described how difficult it is to establish skills that require an uninterrupted sequence of actions. However, with much practice, some people are able to learn to do some every day activities smoothly. A problem arises when conditions change, which they often do. For example, a person may be able to set the table at home, clear the table after a meal and wash up the dirty dishes. One might assume then that the person can also do these skills in a new house, or with a new roommate present or when the furniture has been rearranged. However, many people find that even small changes in the environment make it very difficult to complete routines that they know very well.

Communication is dynamic and full of surprises. Each time someone says something, it is different from the last time they said it. These continuous changes create a challenge for people who rely on automatic movement sequences to participate. People who speak are often criticized for preferring to converse only on certain topics or for repeating the same questions. I believe that these preferences may be related to the need to create some predictability in the conversation in order to participate.

Donna Williams, an author with autism, describes her experiences as exposure anxiety in her book, *Exposure Anxiety – The Invisible Cage* (2003). To her, exposure anxiety is “about feeling your own existence *too close up*, too in your face” (p.10-11).

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The more I wanted to say or show something, the more my own Exposure Anxiety was tuned in, hanging on my every expression. My body, my facial expression, my voice and my words were pulled about by some wild horse inside of me. I'd want to say I was sad, my face would be beaming. I'd want to sit calm and still and enjoy a sense of company, my body would be propelled into wild diversion responses demonstrating discomfort and hyperactivity. I'd try to tell someone I liked them and swear at them, try to show caring and be compelled to do something to repel them (p.103).

She asks some questions that are like your questions in the piece below:

Why can someone with Exposure Anxiety be expressively and naturally laughing out loud out in the back garden but somehow 'stuck', compliant, or performing when in front of others? Why they can't get together to make breakfast once you are up, or run the bath, or get dressed, but seem to do a whole range of things which might prove they were capable of these? Why might someone with Exposure Anxiety be able to initiate communication with their own reflection and yet unable to respond as themselves when shown affection? Or be able to initiate an activity, but when you try to initiate exactly the same activity with them, appear uninterested, distracted or disowning? Why, although they have an ability, do they appear to freeze and become incapable in front of others or when asked to perform a task on command (Williams, 2003, p.21-22).

People who use physical and emotional support to type their communication have similar difficulties. Some folks who started out typing with physical and emotional support, now type without direct physical contact. However, the presence of a 'facilitator' is still an important part of their communication. Jamie Burke, a young man with autism, has learned to type without physical support and now reads aloud what he has typed. His supporters wrote an article about his journey toward independence in the article Broderick, A.A., and C. Kasa-Hendrickson (2001). "SAY JUST ONE WORD AT FIRST": *The Emergence of Reliable Speech in a Student Labeled With Autism*. JASH, 26(1), 13-24. The progress and challenges of others can be an inspiration to us all.

Andrew: Martha, please explain what happens to people who are more independent communicators when they are stuck, or don't they get stuck?

Thomas McKean is a person with autism who speaks. In his book, *Soon Will Come the Light* (1994) he has described his experience with getting stuck:

There are, on occasion, still times when I want to talk, but I can't. I can try and try and try, but I can't talk. There is a fear holding me back. I do not know what it is I am afraid of, I only know that it is a feeling of fear unlike any other feeling of fear I have ever known. It is not that I do not want to talk, it is that I am unable to at that moment (1994, p.39).

Martha has worked with hundreds of children and adults with autism, in homes with families, in schools with teachers, and in community settings with families and supporters. She is a leader in an international effort to integrate information about the effects of movement differences in all aspects of an individual's daily life, creating communication supports that are respectful, functional and meaningful to the individual and others. Martha is co-author, with David Hill, of the groundbreaking article "Moving On: Autism and Movement Disturbance" published in the journal *Mental Retardation*.

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A LESSON FOR THE TEACHER

Beth Komito-Gottlieb, Bridges' principal facilitator who has helped everyone in the group, reflects on an experience of one of our group. It does not illustrate FC, but rather the "deep listening" and being present and attuned to us that is so helpful in our good friends who do not live directly with autism.

For longer than I like to admit, I have supported and become friends with many autistic people. In the course of these relationships, I often find myself wearing the hats of teacher, counselor and facilitator. While the function of these roles can be somewhat different, they all tend to come with the presumption on the part of others that you have some knowledge and leadership abilities. It is a tremendous responsibility and honour when others invite you to guide them in one way or another and I must admit that being a leader can be heady stuff. And there lies the danger!

My friend Andrew related an experience recently that reminded me that, for those of us who teach and guide and facilitate, there are lessons to be learned from people we may sometimes think of paternalistically--but only if we step out of the way and give them the opportunity to take the lead. This is especially important for people with autism because we have come to understand that initiating things can be among their greatest challenges. So while we are busily working alongside them, listening and searching with them for enabling strategies, we should watch for the moments when our friends with autism are ready to take charge. This was powerfully illustrated in the story Andrew told me. I asked Andrew to write it so that we could share it with others.

Taking charge of my life: What happened when I went biking with Travis

I was biking with my friend Travis and my parents were visiting his wife at their house nearby. We had ridden a while. Travis wanted to go on, but I signed "Toilet" and rode off to my home. I think he thought he should stop me. My parents were not in the house, so I used my electronic key. My friend Travis followed me to my room. I showed him my bathroom and told him "Bye". I used the toilet. Then, as I like to have a bath at bedtime, I turned on the tap and put in the Epsom salts. He went to call my parents. It was OK that he called them, but I think it was wonderful that he followed me and let me take the lead.

When Andrew told me about this event, three thoughts collided in my mind. "Well done Andrew!" "Hurray for Travis!" and "What if Travis had tried to prevent Andrew from doing what he knew he needed to do?"

Andrew had been working toward this moment for months and years, learning how to ride a bike when he was a teenager; sign dozens of words; use his electronic key; run his bath; and navigate his neighbourhood. Being able to initiate and use these skills independently, in the presence of someone new, skills that were not necessarily connected to each other when he learned them--that was another matter. But on that summer day, Travis, a young man who had little of what we sometimes label "experience" and had known Andrew for a relatively short time, first tried to convince Andrew to continue on their planned route, and then gave way, following rather than strong arming Andrew into doing what he, the "caregiver," wanted. And, by giving way, he really supported Andrew to do what he needed and knew how to do.

Andrew and Travis have both proven to be teachers for me. And their lesson gives me reason to pause. What might have happened if Travis had taken a more controlling approach? And what of all the people who are controlled every day and not given the chance to lead the way. Thank you, Andrew and Travis for this lesson.

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BULLETIN BOARD

Andrew Appeals

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. 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. 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 are doing quite a lot already on our own but Bridges Over Barriers needs funds to realize our bigger dreams. We need to appeal to other people to help us. I am an active member of 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. I asked GSA to shelter gifts made to Bridges Over Barriers in its early years. GSA directors and our families and friends have given a total of more than \$12,000 in nine months, and GSA's Board kindly agreed. GSA's Treasurer issues official receipts for gifts. Two professional people, friends of Bridges, are willing to advise GSA on worthy projects for which the funds can be used.

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.

OUR VISION

Bridges over Barriers is a focus for friends 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 group 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.

Andrew first had the idea of Bridges Over Barriers in July 2005: "FC is so important that I want to start a place of refuge and organization for FC and life planning and autism. The Autism Project I want to organize would be in a place where I can greet friends, host meetings, teach about FC and other things that help us. It is about building bridges, not walls. This is so happy-making. First the FC Gathering and then the world. I am really serious about this!"

This is our message to people who would like to be guests at our gatherings. 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, and we need our visitors to respect our efforts. Please be aware that, during our sessions, we the communicators lead the conversation and our parents and friends support, observe and record what we say. Supporters and visitors do not speak during the communication sessions. 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.