

BRIDGES-OVER-BARRIERS

THE COMMUNICATION BILL OF RIGHTS

I have the right:

- to express feelings and needs
- to be listened to with respect
- to understand communications
- to request information
- to have access to information
- to learn about myself
- to learn about life
- to aids, services and resources
- to be included in social interaction
- to be offered choices
- to reject

Based on original models by American Speech-Language and Hearing Association and Compic Scope in Victoria, Australia. For a free download of the graphic version: <http://www.scopevic.org.au/bill%20of%20rights.pdf>

ODE TO AUTUMN

I love autumn.
My body loves it too.

My mind is clear
as the breeze
that blows the leaves
down to the ground.

My eyes love the sights
as the colours change.

My ears look forward
to hearing the leaves
crunch and crinkle
under my feet.

My mind remembers
that in the fall
we eat squash and pumpkins.

In the autumn, I am glad
of the break from hot summer.

My feet are planted in this season
and I hope I can hold on to it.
-AB, 24 September 2008

TOWARDS SUPPORTED DECISION-MAKING

At our Bridges gatherings, we talk about issues involved in making choices and having more control over our own lives. For our thoughts about these questions, see pp 2-3
What top ten things do I want people to know so they can support me well? How I fit in the world: Do I feel included? With my neighbours, my family and friends, my city, my country? What would make me feel more included and comfortable in the community? Now I am an adult, what changes might I like in the way I am supported? How well included am I in making life plans?

THE FIRST BRIDGES GRANT

A Toronto man received a grant so experienced facilitator Beth Komito-Gottlieb could introduce him to supported typing and his support circle and team to the most effective ways of helping him to express himself. See page 4.

CHANGING THE WORLD...

...ONE VOICE AT A TIME

DEAL Communication Centre, in the Australian State of Victoria where FCT began for people with little or no functional speech (pages 5-8)

NEW BRIDGES INITIATIVES

Three new projects are in the planning stages (page 9):

- The Bridges tech system to streamline real and virtual gatherings of communicators
- The Bridges movie
- The Bridges guide to supported typing and AAC

THE BRIDGES DREAM AND HOW TO HELP

Bridges-Over-Barriers has a powerful vision—of people who cannot speak being enabled to express themselves and being listened to with respect, so that they can direct their own lives. See more on page 10.

HOW TO REACH US

Postmail may be sent to Bridges-Over-Barriers, 23 Waverly Drive, Guelph, ON N1E 1G6.

Send email to ebloomfi@uoguelph.ca (Subject: Bridges).

For links to past newsletters, visit the Bridges webpage at: <http://www.ont-autism.uoguelph.ca/Bridges-2007.html>

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TOWARDS SUPPORTED DECISION-MAKING

In Bridges gatherings we often talk about issues involved in making choices and having more control over our own lives. These discussions are timely now that the Ontario Government has passed an act that is meant to promote more social inclusion and to give people with developmental disabilities more choice and control over their lives. Bridges members have been asked for our thoughts on Individualized Funding and the supports (like pillars of a bridge) that are necessary to make IF work. These pillars are: Independent Planning & Facilitation; Circles/Networks of friends in the community; support groups of families and persons with disabilities to share experiences and good ideas (Bridges is an excellent example); and ways of ensuring that funds are spent well for the helpers and resources we need. Below is a record of our early discussions. We will go on talking about these ideas. In the right column are earlier thoughts by a Bridges man whose good life is supported by some IF.

My excellent life (2 July 2003)

People should know
what a wonderful home I have
and the things I do every day.
I have my own home and it revolves around me.
Everyone who comes here is friendly to me.
They listen to me and respect my decisions.
I am comfortable and safe here.
I'm happy with our progress.
Well planned and not stressful.
I grow into each step.

Individualized Funding (May 2005)

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.

What top ten things do I want people to know so they can support me well?

--I am happy now. My top two are: To go to the farm and live at the farm.

--People should know I am smart, though hearing-impaired. I like swimming, to go for a walk, play bingo, have friends, go home afterwards, and to my [day program].

--I'm intelligent. I need encouragement, not bossing. I have a diet which I need to follow. I like to make meals with friends. I like to teach-- about our way of being in the world: How we need support but not parenting. I hope to get our Bridges centre going. My days must be flexible. That's enough.

--I would like them to know that I am smart. I can do things. I do not like to be talked down to. I think they should know that I have a good life with my parents. I love them so much. I want to be close to them. I am not an angel and sometimes do stuff that they will not like. They should be patient and not get mad and be my friend anyway.

--Support people need to be flexible and encouraging. So keep trying in many ways: don't give up till you try many ways. When we need flexibility but don't have it, we get agitated. I will say No in many ways. People will know by the way we are in the world.

--I need people to hear us, when I communicate my way.

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Thoughts about Peter Block's words which Judith Snow sent us:

"Being is our capacity to find our deeper selves in all that we do....

Community is the container within which our longing to be is fulfilled."

--Being is really hard to define.

--Finding my deeper self is not hard, but expressing and showing it is the trick.

--I don't know so much how to be myself yet, but now we live at ----, I think my sister and I can be more ourselves.

--Community is more than a container.

--Community is very lively and like a kind of family.

--Community is finding your place with others and making a network of friends.

How I fit in the world: Do I feel included? With my neighbours, my family and friends, my city, my country?

--I feel included with everybody, but mostly with family and friends.

--I do fit in the world very well. I need to control my impulses and I need to learn how. It would be better if I could be calmer when I am with people.

--I am included at the farm. I can wander and not get into trouble.

--I feel that I fit in my house and community. I am known in the community and have places to go.

--I love to vote in the election. I carefully listen to the candidates and my family's ideas. Then I decide. I feel it is my duty to show autistic people can be good citizens.

What would make me feel more included and comfortable in the community

--To go for walks and people say Hi and know my name.

--I think being known and being with a good person like you and Dad.

--I like spending time with my brother..

--I get to do things comfortably because people help me. I become familiar and do more things. My dogs build bridges for me in my neighbourhood: people can better relate to me and respect me.

--My sister helps. My world is safer and better now, but I'm not sure about the future.

Now I am an adult, what changes might I like in the way I am supported?

--I am happy with the support I have.

--I want to get out more.

--I think that people treat me like a man.

--I would like to be treated like an adult.

How well included am I in making life plans?

--Happy with my life at this point.

--I don't think my life plans could be made differently.

--I try to be included in all things about me, which is how my life has been designed.

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THE FIRST BRIDGES GRANT

In August 2007, Bridges was asked for a grant by a Toronto man who wanted help “to learn how to use supported typing to express myself.” With his support team, M- explained: “I would like to learn how to respond to varying supporters and how to correct if they have said something that I don’t mean. I would like to try a variety of options in terms of equipment and boards, with the expertise of someone who has taught and supported others with Autism how to use typing to communicate. I would also like to learn how to initiate communication and increase my fluency in giving direction, choice making and participating in more complex social exchanges. In addition to the ways that I can help myself, I’d also like to add my voice to others that are working towards awareness, capacity building and advocacy for people of all abilities and needs. Eventually, I would like to be an independent typist. It is difficult to know what will be possible in the future, but I have already made progress in my ability to tolerate touching and allowing others to help me to use this approach. As I become more confident and more able to control my body to use typing to communicate, I will work with my team to see the extent to which independence is possible in the future.”

These were large hopes for a 4-month project, but Bridges (through the GSA Board) was pleased to support the goals of M- and his support team. Beth Komito-Gottlieb, a founding member of Bridges and an experienced facilitator-trainer, met with M- weekly in the August-December period of 2007. She was also able to discuss likely approaches and techniques with M-’s support team and circle of family and friends. “They proved a wonderful group of learners in that they took seriously the information and suggestions offered to them, in particular the aspects of movement dysfunction that complicate the process of supporting M-’s typing. There can be much physical stress on M-’s facilitators as it requires a great deal of muscle to stabilize his movements. The team members, already a loving and supportive group, interacted with M- in ways that convey to him that they believe in him and are there to support his efforts. They paid closer attention to all of their interactions with him. In addition to making gains in their technique with his typed words, they were all talking, reading and engaging him on more levels than before. M- became happier. At times he was positively beaming.”

Samples of what M- said during the first three months of the grant:

“I like to talk.” “Be ready.” “Keep trying.” “Teach me ask questions.” “Some days I feel bad and some days I feel great just like anyone in the city feels some days and then I go to bed” (*a longer message can take quite a long time for M- to type, sometimes as much as 15 min for one sentence*)

Staff observations: “Since developing his communication with FC, I have observed an increase in M-’s level and duration of attention. I have also noticed his sustained attempts at reaching for the letters- his determination, interest and drive. During verbal conversation, M- also seems to be more present and involved. This may also be because I am speaking to M- in new and different ways since he has been talking with FC. Physically M- allows me to reach for and support his hand with greater ease than before. He also offers his hand.” ” How excited and energetic M- is when he is at the board!”

Beth summed up her observations in this first Bridges grant:

“The Bridges funding enabled M-’s team to get started in a more focused way. It has been a challenge to work with so many people at once, but it seems to have benefited M- greatly. He recognizes that the whole team is behind him on this and he has responded by showing everyone that he is thrilled to know that others recognize more about him than they might have before, regardless of what he might say or do at any given moment.”

An account of the second Bridges grant appeared in Bridges Newsletter 5 (August 2008).

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CHANGING THE WORLD - ONE VOICE AT A TIME

DEAL Communication Centre, in the Australian State of Victoria, works with people who have Severe Communication Impairment (people with little or no functional speech). DEAL is dedicated to "Breaking the Silence" and a world in which everyone who cannot speak has the means and the opportunity to communicate." Dr Rosemary Crossley of DEAL developed the practice and theory of facilitated communication, mainly for people with cerebral palsy, before it became known in North America after 1990. We present here, with DEAL's permission, information about communication support for people who have severe communication impairments. The latest DEAL newsletter also includes "Cheaper Chips: Cheap Text-To-Speech Communication Aids," "Literacy and Augmentative Communication: Useful Websites and Software" and Augmenting the Speech of People Diagnosed with Autism/ASD: Assuming Competence and Addressing Movement" all by Rosemary Crossley. Website at <http://www.deal.org.au/>

Communication is the passing of information from one person to another by any means - signs and gestures, alphabet boards, video displays, speech synthesizers, anything. All people, whatever their age, education, or ability, need to communicate.

Individuals are described as having severe communication impairments (SCI) when their speech and handwriting are insufficient to meet their communication needs. The term is usually used in relation to people with no speech or very little intelligible speech, but it may also be applied to people whose speech, while clear and fluent, is still not meaningful or representative of their real thoughts, for example, people whose speech is echolalic. Most people whose speech is severely impaired also have difficulty with handwriting.

People with SCI and hand function impairments are particularly vulnerable to having their cognitive abilities underestimated owing to the dependence of standardized intelligence tests on speech and hand skills. People with SCI who achieve effective communication aid use may reveal previously unsuspected competencies. Some people with SCI have picked up some reading skills, either in literacy classes or from incidental exposure to written language. These skills will often have gone unrecognized because of the person's expressive impairments.

Many children with SCI find themselves caught in a downwards spiral: assessed as significantly intellectually impaired as a result of their speech and motor impairments, they are placed in a school where their speech and motor impairments are seen as being the unavoidable corollary of their intellectual impairments. They are unlikely to receive an occupational therapy assessment, and speech therapy is likely to be at a premium. The combined effect of continued failure (after all, the student does not have the basic output skills necessary for success), low expectations and lack of therapy is likely to be deterioration or stagnation rather than improvement. The student's behaviour is often as poor as their academic performance.

As assessment of students with severe expressive problems is so difficult, no student should be excluded from a communication training programme on the basis of previous negative assessments.

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Often the training is a prerequisite for accurate assessment. Always give the student the benefit of the doubt. People with communication impairment should be helped to achieve their own goals and be fully participating members of society.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION is the formal title for non-speech communication. In fact, the difference between augmentative and alternative communication is merely the difference between partial and total dependency on non-speech communication. Speech may be replaced or augmented by:

1. gesture and body language.
2. manual sign.
3. handwriting.
4. communication aids.

Communication aids are devices developed or adapted for use by people with severe expressive communication impairments. Because these people have very varied skills, needs and problems there is a large range of communication aids.

Some people with severe communication impairments can use their hands; others cannot, and have to use alternatives such as mouth sticks, headsticks, switches or eye-pointing. Some can read and spell; others cannot, and need communication aids on which language elements are represented by pictures or symbols. Some individuals use wheelchairs which can accommodate large communication devices; others walk and need small, light aids. Some have funding to buy high tech equipment.

A communication aid may be as simple as a piece of cardboard with 'no' and 'yes' written on, it or as complex as a laptop computer controlled with one switch which speaks and allows the user to talk on the phone, access the Internet or type an essay.

The best non-speech communication strategy (or combination of strategies) is the one which allows the person with severe communication impairment to communicate as freely as possible in as many situations as possible to the maximum number of people. Nobody should be refused a trial of AAC resources to see if that would help. The way to see whether someone will benefit from AAC therapy is to give them the therapy and see whether it works.

FACILITATED COMMUNICATION TRAINING

To facilitate is to make easier. In facilitating communication we try to make the task of using a communication aid easier for a person with a severe communication impairment. The degree of facilitation needed varies from person to person, ranging from an encouraging hand on the shoulder (to boost their confidence) to full support and shaping of a student's hand (to enable them to isolate and extend of their index finger so they can point). This training may be most useful for people with severe communication impairments. Facilitated pointing can provide a temporary remedy for the hand function impairments of some of these people, and may result in a permanent improvement in

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hand function when used as part of a structured teaching program.

What is facilitated communication training (FCT)? Most of the time facilitated communication training (FCT) is a better term than facilitated communication (FC). FC isn't an end in itself – it's a stage that we hope people will pass through on their way to improved communication. FCT is a strategy for teaching individuals with severe communication impairments to use communication aids with their hands. In facilitated communication training a communication partner (the facilitator) helps the communication aid user overcome neuromotor problems such as impulsivity and poor eye/hand co-ordination and develop effective pointing skills.

The immediate aim of FCT is to allow the aid user to make choices. People who can make choices can communicate in a way that was impossible before. Once they can make choices we encourage them to practice using a communication aid (a picture board, for example, or a speech synthesizer or keyboard) in a functional manner, to increase their physical skills and their self-confidence and to reduce their dependence on the facilitator. As the student's skills and confidence increase the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aid(s) of their choice independently.

Use of FCT is not restricted to any specific age or any diagnostic group. It's been used successfully by people with diagnoses including autism, Down syndrome, intellectual disability, cerebral palsy and acquired brain damage. We'd say it was worth trying for anybody who isn't speaking, or who isn't speaking roughly around the level of their peers (because we do have clients who have some speech – just not enough for their needs).

FCT generally isn't considered as an option for an individual if they have a reasonable amount of functional speech, or a fluent alternative communication strategy, or the potential to acquire manual signing or handwriting skills easily, or can clearly and unambiguously select nominated items from communication displays, or are able to use other direct or indirect access options such as headpointers or scanning systems (some people can't use these means because of physical control problems, some can't use them for practical reasons - people who walk instead of using wheelchairs, for example, have trouble carrying a scanning system around with them).

Importantly, that list does not include “don't have the intellectual capacity to use it.” Never make any assumptions about the intellectual abilities of anyone who has difficulties communicating. Training first, testing afterwards. On the other hand, that doesn't mean that anyone who can't communicate should be started on FCT. There are a whole lot of other AAC techniques that work well for many people.

Once it's been decided that an individual is a candidate for FCT, it's then necessary to:

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- work out the nature of the problem(s) which are preventing them from accessing communication aids successfully;
- select appropriate remedial strategies, including facilitation strategies if needed
- ascertain what representational systems (concrete objects, pictures, pictographs, written words, letters) are currently meaningful to the potential user
- enable the individual with severe communication impairments to use the most empowering of the representational systems and selection strategies currently available to them by obtaining/making appropriate communication aids and teaching those in the individual's environment how the aids are used.

FCT has enabled some people without functional communication to take charge of their lives, make their wishes known for the first time, and join the life of their communities. Parents have been enabled to communicate with their children. Children who have had only restricted education, or no education at all, have gone into regular classes; some have completed high school and gone on to university. For some people with challenging behaviours frustration has been relieved and behaviour has improved. Of the thousands of people with severe communication impairments who have been to DEAL Communication Centre over the past thirty years, almost all have been able to improve their communication. And communication – any communication, from being able to answer yes or no upwards - changes the lives of people with disabilities, and the lives of their families and friends.

Facilitation is controversial

Facilitated communication has been criticised by some professionals as an unproved technique that is open to abuse and can lead to words being put in the mouth of a person with a disability. That's true enough (what human activity isn't liable to abuse?) but some critics jump from there to the conclusion that FCT should never be used, which is a baby = bathwater error. However, users should certainly be aware of possible pitfalls and necessary precautions.

Facilitation is a last resort.

Facilitated communication is difficult, limiting, time-consuming, and controversial. If you can find any other halfway satisfactory way to communicate with a person, jump at it. If you can't, try FCT – and try to work your way out of it as soon as is feasible. A few people find that after a year or two of FC they can get a bit of speech back. Others find that with sufficient practice they can learn to use communication devices without assistance. Some people find they can work independently some of the time but revert to dependence when under stress. Some people communicate independently on important matters but use FC when they just want to get a simple message across quickly. In any case, the decision is theirs.

Facilitated communication is the worst possible way to communicate. If you can't make any other way work, though, *it's being recalled to life*. Do what you like - but remember what's important.

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NEW BRIDGES INITIATIVES

Three new projects are in the planning stages:

- The Bridges tech system to streamline real and virtual gatherings of communicators
- The Bridges movie to illustrate communication and supported decision-making in people's individual lives and at Bridges gatherings
- The Bridges guide to using supported typing and other forms of communication

1. We need **BETTER TECHNOLOGY FOR USE BY GROUPS OF COMMUNICATORS**, so that everyone can hear and 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 a screen, wall or 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. We need such a system 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 can report progress!

- Our good friend Dr Joan Jory interested her brother Michael who has volunteered his technology expertise to help us update the equipment we use to share thoughts at gatherings, so that our words can be clearly heard and understood and our supporters seldom need to prompt or comment. A guiding principle is that the hardware and software should be both inexpensive and robust.
- The new system will enable us to hold virtual gatherings in times of bad weather when all cannot travel to Guelph, and also when members of the group move away from southern Ontario. Bridges men now live in France and New Mexico, and another is probably moving to Nova Scotia in spring 2009.
- A further benefit is that communicators will try out and become tolerant of various computer devices, probably also widening the circle of communication assistants and allies in their lives. Other adults with autism and their support circles have heard about Bridges, and are interested in knowing more. Our tech system will allow them to observe a Bridges gathering, so they can decide whether to be included.
- The system could be used for PATH planning events, when participants are more comfortable typing than speaking. The system has potential value for other groups and individuals who use alternative modes of communication because they cannot speak and who want to be connected. Others are looking to our group as a pioneer in supporting self-expression by people who do not speak with their voices.

2. The **BRIDGES OVER BARRIERS VIDEO** will 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 personal video made about one of our members in 2008 and also 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 of Newsletter 5 for more of our ideas about this movie or film. We would like to make a really good movie, perhaps of 50 minutes which could even be shown as a documentary in a program like TVO's Human Edge.

3. The **BRIDGES BOOK AND INFORMATION PACKAGES** will explain our right to communicate in our own way, our responsibility to think about options and make choices about our lives, some context about other ways we communicate and are listened to, information about how supported typing works so people understand that it is really we who are doing the thinking and composing while our supporters steady our hands and muscles; and how important Bridges-Over-Barriers is to us as a community of communicators.

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THE BRIDGES DREAM AND HOW TO HELP

ANDREW EXPLAINS HIS DREAM IN JULY 2005:

Communication is so important. I want to start a place of refuge and organization for communication and life planning. This is my dream of the Autism Project. I want to be in a place where I can greet friends, host meetings, teach about communication and being in the world, and other things that help us. For now, it can be based in my home. Later it must be bigger. This is so happy-making. First the Bridges Gathering and then the world. Some day I want a real place that is a community of communicators. Until then we do our best.

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. We welcome people who use ST and other communication strategies to develop our skills as communicators and to share technology ideas and friendship. It is about building bridges, not walls. I think we have become important to each other in a powerful way. I think that our gatherings can be made more regular and frequent. We can talk more often online or by email. We can teach others.

Families and friends meet all the expenses of our regular activities, but we need help to realize the bigger dreams. Friends of Bridges have given money and, from spring 2007, we have proposed ideas of how Bridges funds could help 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, by providing training and practice for person-plus-team in supported typing
- Recruiting and training new communication partners and allies, individually or in groups
- A major event, like a conference with workshops, for all people who care or are professionally concerned with supported communication.

Three new projects that will tell people more about Bridges are described on page 9.

Guelph Services for the Autistic, the not-for-profit corporation of which I am an active member, shelters 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 professional friends of Bridges advise the GSA directors on projects that should be helped, and the GSA Treasurer and Board have been very helpful.

If you would like to help Bridges-Over-Barriers, please make your cheque payable to “Guelph Services for the Autistic” with “Bridges” on the subject/memo line, and send to GSA Treasurer (Attn Bridges), 16 Caribou Crescent, GUELPH ON N1E 1C9.