

# BRIDGES OVER BARRIERS

In my life I have many friends,  
but now my Bridges friends are a dear part.  
My friends and I 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 help.  
Bridges is important  
to help ourselves and others  
to keep communicating.

Our Bridges group gathers in Guelph for a day every 4-6 weeks, except in the deep midwinter. Guests and observers are welcome, and we ask all to note this protocol: *Bridges over Barriers is a group that has been created by us as we grow as communicators. It is not easy for some of us to focus on typing what we want to say, and we need our visitors to respect our efforts. Please be aware that, during our morning and afternoon sessions, we the communicators lead the conversation while our parents and friends support, observe and record what we say. We hope that, if you are looking for evidence, you will see that we are a successful group of communicators. We will be happy to discuss your observations and questions during the breaks and by email afterwards.*

## BRIDGES GIFTS AND GRANTS

Bridges over Barriers is so important that we want to help more people to express their thoughts and be listened to with respect. Two years ago we started a special fund, to which our families and friends have given nearly \$19,000. This year, generous gifts to Bridges have been made in honour of the long life of Charles Newton Carscallen (1906-2007), who was Betty Marmura's father and Tim's grandfather. We thank all the donors and the Marmura family for suggesting Bridges.

The first special grant from the Bridges fund was made in 2007—to a Toronto man who asked for help for himself and his whole support team to *“learn how to use supported typing to express myself. I would like to learn how to respond to various communication partners and how to correct if they have said something that I don't mean. I want to learn how to initiate communication and increase my fluency in giving direction, choice making and participating in more complex social exchanges. 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.”*

*GSA administers the Bridges grants—we appreciate the help of Susan Honeyman and Andrew Foster as trustee-advisors and of John Verhart as GSA's treasurer.*

### Read More Inside

Page 2-3: Insights and interactions at Bridges gatherings in 2006-2007

Pages 4-6: The Right to Communicate, recognized in Article 19 of the United Nations Declaration of Human Rights as fundamental of all other rights is spelled out by TASH for people who do not speak with their voices. *“Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.”*

Page 7: Why “Supported Typing”

Page 8: Giving to Bridges over Barriers, and how to reach us.

# BRIDGES OVER BARRIERS

## INSIGHTS AND INTERACTIONS AT BRIDGES GATHERINGS

### SPIRITUALITY (November 2006)

...Being in touch with God. My spirituality is everything now that I can express myself ...

...Spirituality is talking to God and obeying what he says to do. I think that we connect with each other by talking and listening to each other. I feel connected when I am at the farm and in church.

...I think that spirituality has to be about abundant life, not behaviour.

...Spirituality is faith in life eternal and in a caring and loving God who never leaves me. God is my best friend and I talk to him every day. God gives me peace and strength to accept my disabilities. I am always aware of spiritual things because I have lots of silence in my life.

...By seeing the miracles all around me and counting my blessings, I feel some sense of spirituality in my soul. I hear an inner voice in my head that is from a higher being. It might be God or it might be my connection with others, but I must be still and listen. Nature and peaceful places make it easier for me to listen. I think God is everywhere and in all of us.

### INTELLIGENCE TESTING (August 2007)

...I feel that these [traditional IQ] tests are a further way of handicapping us.

...I know that we are smart and he should not have to prove it.

...I think it is supported typing that works.

...The people who don't believe in ST need to open their eyes and see that we are talking and using our own words. We are very smart.

...We need to talk with ST to let people know what we want and think about things. We should teach others to talk with us using ST.

### INTERDEPENDENCE (May-July 2007)

...We are always being told we must become more independent, in communication and our whole lives. We try our best...

...I think I can be independent if people encourage me and let me try new things without being afraid I will not do well. I think I would like to be more independent. I would like to type by myself. I would like to work in the barn by myself. I like learning new things so I can be independent.

...I want to have a friend to be with me and go places. But I want chances to be more adult so the person needs to be able to know when to help and when to say "Go for it!"

...I want to be more independent but I still depend on others to make connections.

We need to be allowed to make our own choices and to try new things. People need lifelong education and recreational opportunities.

...But nobody is absolutely independent. We all need each other.

...Everybody needs companions and it would be a lonely world if we were left completely alone. I believe that my family and housemates benefit from my friendship and company and humour.

...I like to feel independent and respected when people listen to me and don't just not force me to stay on track.

...We are all interdependent. I do not want to be independent.

...I understand about being interdependent, but I think that we autistics get the message that nobody needs us.

...We need each other because we cannot do everything by ourselves. These are ways I help others:

I help others by listening to them talk

I help them organize their thoughts

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## INTERDEPENDENCE *continued*

I think we give good supports by listening to them.

I think we need each other.

I help D-- at the farm and D-- helps me by letting me come to the farm.

I help feed the horses and clean out the stalls.

I think we all work together at the farm to make things work.

## JOB DESCRIPTION FOR A NEW FACILITATOR

(June 2007; requested by GSA Board)

...to be my friend and to believe in me.

...to be a good listener and here with us.

...a kind person to understand me and to be patient.

...needs to have faith in the person and to be willing to make mistakes.

...a good person who understands that I am smart.

...needs to be cautious about assuming my intellect—and know I am intelligent but challenged.

## HOW DO WE FIND GOOD FRIENDS?

(August 2007)

...I don't know. Who will be friends with me? I am different. People feel afraid of me.

...I think they are just there and we find them as we go along.

...I think friends make new friends, not by ads in the paper. We are friends here and more are coming.

...This is where we need our family to intervene. I think the Bridges group should publicize itself so that more people get involved in supported typing.

“MY WORDS AND MY FRIENDS HELP ME TO...” (August 2007)

...feel good about myself.

...do the things that matter to me.

...tie together my life; my words are a bridge to my friends.

...enjoy my life better. I like talking to my friends and I like visiting with them.

...express myself and have a genuine social experience.

## EXPLAINING BRIDGES TO OTHERS

In mid-May, Andrew hosted a small gathering with some visitors from Brisbane, Australia, who belong to a similar group there, called the Brotherhood of the Wordless.

Tim explained that Bridges “does things like language and communication and is an interfaith group of very close friends, and that is the most important thing about it.”

Rodney, for the Brotherhood said, “We do creative writing and we have published some of our work and had a documentary made about us.” He added: “This has been a wonderful time to connect with fellow brilliant-minded FC users to show others in the world that we are valuable and worthwhile”

At a later Bridges meeting we showed the Brotherhood's DVD and book of poetry, called “Tapping on the Heart of the World.”

At our Bridges gatherings, we have also viewed various videotapes about our mode of communication.

An article based on our thoughts about spirituality was published in the Mennonite Brethren Church's national newspaper for April 2007.

# BRIDGES OVER BARRIERS

## THE RIGHT TO COMMUNICATE

### TASH RESOLUTION ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION METHODS STATEMENT OF PURPOSE

The right to communicate is the means by which all other rights are realized and is, in itself, a basic human right. All people communicate and have the ability to make and express choices, although it may take a patient and skilled person to elicit and interpret such expression. In the name of fully realizing the guarantee of individual rights, we must ensure:

- that all individuals have a means of communication which allows their fullest participation;
- that people are given access to assessment in a range of various communication methods;
- that people can communicate using their chosen method in all of the settings in which they spend time; and that their communication is understood and heeded by others.

Where people lack an adequate communication system, they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because he or she has been diagnosed as having a particular disability. Access to an effective means of communication is a free speech issue.

### RATIONALE ACCESS TO COMMUNICATION

All persons with disabilities should be provided therapy and training directed toward permitting them to communicate freely. All people with communication disabilities should be given the full opportunity to use the method of augmentative and alternative communication that works best for them. "Access" includes: a) access to assessment to judge the suitability of a range of methods, b) access to training in the method found to work best for the individual, and c) access to needed equipment and trained support people both in the short term during training, and in the longer term for continued use on a daily basis in all of the settings in which an individual spends time so the individual can use his/her preferred communication method across environments.

### EDUCATION

Instruction in communication is an essential element of the education of people with communication disabilities. People using augmentative or alternative communication must be given any assistance necessary in order to communicate with others at school or in their educational program. Any equipment, training or staffing necessary to enable communication to take place must be supplied, both to that person and to those with whom he or she wishes to interact on a regular basis. The collaborative education team must ensure that all such communication equipment, or comparable equipment, follow the person to his/her other settings and when transitioning to post-school environments.

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## FREEDOM TO COMMUNICATE

People with communication disabilities must be allowed to use the communication system of their own choice in all communication interactions in any setting. No person should be able to veto the use of another person's preferred communication method and in any instances where such use is forbidden, there should be recourse to the individual and his/her family members through the legal and protective systems.

## FACILITATED COMMUNICATION

Facilitated communication is one of many augmentative and alternative communication techniques that is used by some individuals who cannot speak or whose speech is limited. The method involves a communication partner, typically called a facilitator providing physical and emotional support as the person points at pictures, letters, words, or other symbols.

Facilitated communication is controversial. In some research studies, individuals using facilitation have not demonstrated that they were able to convey their own thoughts through the method. Some studies have revealed that individuals have been influenced by or have picked up on cues from their facilitators. In other studies, individuals have demonstrated the ability to express their own ideas and to do so without influence or cue seeking. Many individuals with disabilities have progressed from supported typing to independent typing.

The question of authorship can become particularly controversial when the subject of what has been communicated concerns sensitive issues. Such topics may include, for example, preferences about living arrangements, allegations of abuse, and selection of personal assistants. As with all other methods of augmentative and alternative communication, TASH supports access to assessment to determine if this method of communication works for a particular individual, access to training in the method for both the individual and the facilitator, and, if demonstrated to be a successful method for the individual, access to the method and a trained facilitator for use in the long term in all of the settings in which an individual spends time. TASH encourages careful, reflective use of facilitated communication. TASH encourages facilitators to work in collaboration with individuals with severe disabilities to find ways of monitoring authorship when using facilitation. To this end, TASH encourages use of multiple strategies, including, for example; empirical research methods (qualitative and quantitative) and transitioning to independent typing.

## LEGAL ISSUES

People using augmentative communication must be permitted to use the system that works best for them and that they prefer in court as in other settings. Any person using a communication strategy requiring the involvement of another person to receive and relay their communication must be permitted to use the partner of his/her choice in court. Each state's protection and advocacy system should develop the resources needed to support such full participation in the legal process.

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## PRESUMPTION OF COMPETENCE IN DECISION-MAKING AND ADVOCACY

People are presumed to have an active interest in decisions affecting their lives on a short-term and long-term basis. In planning or decision-making on a person's behalf, that person's participation must be ensured regardless of the formal communication modalities used. This may include the involvement of allies, advocates and communication partners before and after meetings, and may also include the involvement of a "communication ally" during the course of the meeting.

THEREFORE BE IT RESOLVED, THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field:

- regards access to augmentative and alternative means of expression an individual right.
- encourages its membership to become informed about the complexities of augmentative and alternative communication methods, training, and practice and to stay informed of new research and practice related to communication methods.
- encourages rigorous and ongoing training for people who provide training and support in all methods of augmentative and alternative communication.

It is important not to silence those who could prove their communication competence while using augmentative and alternative means of communication or any other method of expression.

*TASH RESOLUTION ORIGINALLY ADOPTED NOVEMBER 1992, REVISED DECEMBER 2000*

<http://www.tash.org/IRR/resolutions/res02communication.htm>

<http://www.tash.org/>

*TASH is an international membership association leading the way to inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.*

*We have numerous chapters and thousands of members from thirty-four different countries and territories. Since our inception over thirty years ago, TASH has gained international acclaim for our uncompromising stand against separatism, stigmatization, abuse and neglect. We actively promote the full inclusion and participation of persons with disabilities in all aspects of life.*

No other form of communication (that involves augmentative means) has had to undergo such rigorous tests as the use of FC by persons with autism. Is it reasonable to apply standards to this one communication intervention and to people with autism that are not applied to other communication interventions or to other people who do not have the use of their voices?

[Of facilitator influence]: Communication always involves an influencing interaction between the communicator and the receiver of communication (Ferguson and Horner 1994).

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## SUPPORTED TYPING — WHAT DO WE MEAN ?

Our group and some other people with the same dreams propose the term “supported typing” for the form of augmentative communication that we use and are trying to encourage through Bridges. In the past we used “facilitated communicating” (FC for short).

### WHY IS SUPPORTED TYPING BETTER FOR US?

1. It describes more precisely what we do. We distinguish the thoughts and language in a person's mind from the physical actions of actually expressing these in ways that other people can reliably understand by typing on a letter board or electronic device that has a Qwerty keyboard. While our people cannot reliably express themselves with their voices, they can read and know how to spell and what words mean. They have language and are literate. They also want to make themselves understood. Their poor motor control means that they need support to get their meaning out in ways that can be read and or heard by others.

2. We focus on the physical and emotional support that people with severe neurological and movement differences may need to steady their hands to type. Physical support may include "backward pressure" of a partner raising the person's typing hand between each keystroke--so that the nerves and muscles don't just continue randomly and the person has time to choose which key to hit next. Emotional support means the interpersonal bond that includes listening to and believing that the person has something he or she wants and needs to say.

3. Facilitated communication (FC) or Facilitated communication training (FCT) means a wider range of augmentative communication strategies by people without functional speech who augment their speech by using communication aids with their hands. This may include pointing to picture symbols, words or abbreviations, as well as the more specific strategies of supported typing.

4. Since the term became quite widely used in the early 1990s, FC has acquired other meanings. Detractors (some of whom cannot believe that persons with autism think or have anything to say) have declared that the "facilitator", perhaps unconsciously, is the real author of the message. Unfavourable publicity about FC for more than a decade was extrapolated from failures and mistakes when educational and social services took it up too easily as an easy strategy for everyone who didn't speak. Public opinion swung against FC, despite well documented success stories. Educators and administrators became so nervous that they abandoned all efforts to encourage communication by people who do not speak. By using another term, which is also more exact, we may sidestep the misunderstandings and help people who could really benefit.

7. We need to allow for the other ways that people who cannot speak may communicate their thoughts, wishes and needs—by sign, gesture and pointing--and for the processes by which some supported typers may become less dependent or even independent of physical support.

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## BUILDING BRIDGES

### OUR VISION

The vision of Bridges builds on our small community of adults who have been meeting a few times a year since January 2004. We dream of a place of refuge for people who live with severe challenges of communication and movement, which can also be a centre of expertise and support to help more people to express themselves.

At our regular gatherings in Guelph, with family members and friends, we use supported typing to talk about everything from spirituality to special diets. We share a meal and snacks and a walk. We have viewed videos on topics important to us, and have started to share other interests such as music and painting.

We need to tell everyone that people who do not speak because of movement and communication disorders can be helped to express themselves reliably. We ask 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. We need to encourage and train more communication allies who will provide the physical and emotional support that we and others need. We want family members and friends to feel more confident as communication partners. Children and teenagers with autism should 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 difference.

### ANDREW APPEALS

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. GSA is sheltering gifts to Bridges in its early years. GSA directors and our families and friends have given a total of more than \$19,000 in 24 months. As a registered charity, GSA can issue tax-creditable receipts to donors and hold funds in trust for worthwhile purposes. Two professionals, friends of Bridges, advise GSA on worthy projects that should be helped.

These are some ideas of how Bridges funds could promote more listening to, understanding of, and respect for people who do not speak with their voices:

- a) Materials and events to increase awareness of supported typing and deep listening
- b) Information for family members and friends to explain supported typing so they know for sure that communicators are expressing their own thoughts
- c) Recruiting and/or assessment of new communicators
- d) Training of person-plus-team in supported typing (this is what Bridges' first grant is doing)
- e) Recruiting and training groups of new communication partners or "communication allies"
- f) A major event, like a conference with workshops, to attract all kinds of people who care or are professionally concerned with supported communication
- g) Our larger and longer-term dream of "a place of refuge and organization for communication and life planning and autism."

If you can give, please make your cheque payable to GSA (with Bridges over Barriers on the memo line) and send to: GSA Treasurer, 16 Caribou Crescent, Guelph, Ontario, N1E 1C9.

### HOW TO REACH US

Postmail may be sent to the above address (Attn: Bridges). Send email to [ebloomfi@uoguelph.ca](mailto:ebloomfi@uoguelph.ca) (Subject: Bridges). For links to past newsletters, visit the Bridges webpage at: <http://www.ont-autism.uoguelph.ca/Bridges-2007.html>