

Bridges-Over-Barriers
OUR COMMUNICATION MATTERS!
MAKING THE BRIDGES DREAM COME ALIVE

Report by Andrew Bloomfield

Guelph, August 2019

We hosted some Bridges events here in mid-August for various people in small focused groups. The idea was sparked by the interest in my new film *It's My Voice—Believe Me!* That was shown at our Steps Toward Inclusive Community event last March 30. My Bridges Dream dates from 2004 when I founded Bridges-Over-Barriers and invited others to gather regularly in Guelph to share our struggles, strategies and dreams. We have had more than 100 gatherings and published information and personal experiences in print and video.

However it is still very hard for people without voices to get training and support in whatever mode of communication works for them. Skeptics and negative thinkers may deny the way we express ourselves. We know of nonspeaking children and adults who could respond to assessment and training but are prevented by people in authority. People who would like to train and practice as communication facilitators are discouraged.

We offered three days of linked events including theory and practice, technique and meaning:

- Individual assessments of three young adults with little or no experience of Supported Typing;
- Opportunities for in-depth training in best practice by four Bridges members towards lessening the amount of physical support we need;
- A Bridges gathering on the Wednesday around one of our traditional lunches;
- An afternoon forum of my close friends to consider strategies for ensuring that my communication is respected and believed by people in authority;
- Two evening discussions to which friends and allies were invited to address questions of the validity of Supported Typing aka Facilitated Communication and what we could do to show that this mode of communication is real for at least some people.

Two ideas we came up with were threaded through several sessions.

1. ---One was to try our best in our communication skills so we could gradually lessen our physical dependence on our facilitators. We talked about this in the evening discussions and Tuesday afternoon forum and practiced it Tuesday morning and all of Wednesday.
2. ---The other idea was to make it possible for each communicator who wishes to earn “communication credentials”. These are documents based on a dossier or portfolio with evidence of competence in various skills, showing that we understand our options and can reliably express our wishes and priorities. I want to do this and I know some other Bridges members do as well. We still have to work out how exactly to do it.

Our event was important and valuable to different kinds of people. We were fortunate to have Pascal Cheng here again as mentor and coach—he is a Master Trainer based in Burlington Vermont who visited me and my team four years ago when we made a short video. Judi Henry, my lead facilitator was here the whole time. Heidi and Jesse, two of my tutors were here for most of the time. A precious few were interested in training to be facilitators. Several directors of Friends of Andrew Bloomfield (FAB) and Guelph Services for the Autistic (GSA, which shelters Bridges-Over-Barriers) also attended, with my philosopher friend David DeVidi leading the two evening discussions and the FAB forum on Tuesday afternoon. We had 13 people taking part on Monday and 14 on each of Tuesday and Wednesday. Thanks to all for your contributions!

I thought Our Communication Matters! events were successful. I was very happy about the Bridges gathering on the Wednesday and so glad that the other Bridges members also want to become less dependent and like the idea of documenting our communication skills so we can be taken seriously and believed by people in authority.

Our Communication Matters! Guelph in August 2019: timetable

Times	Day 1 (Monday Aug 12)	Day 2 (Tues Aug 13)	Day 3 (Wed Aug 14)
9-10:30		9-10: AB with J, J, P, H: Road to Independence & brushing up best practices.	Bridges-Over-Barriers FORUM Typers arrive with supporters, up to 4 parties. Conversation with familiar support mentored by Pascal and Judi in priorities for reliable communication.
10:30-12		10-12: Pascal: Assessment 3 In Upper Room. AB and team continue new exercises with Judi.	
12-1	Judi and Pascal arrive	Lunch	Lunch
1-3	Assessment 1 : Upper Room	FAB Forum on communication strategies to lead my own life.	Continued sharing of struggles, strategies and dreams. Discussion of Credentials idea and Documenting Communication Skills.
3-5	Assessment 2: Upper Room	Recognition and Rights: how to have decisions respected. DD	
5-6:30	Supper	Supper	Guest leave...
6:30-9	The Right to Communication and Supported Typing: the Controversy, the Science and the Potential. Presentation and discussion led by David DeVIdi.	Discussion led by DD: Ideas of Documenting Communication Skills: is there value in a communication skills dossier or Communication Credentials?	

Dave helped us to understand negative attitudes to Supported Typing and encouraged us to think about convincing people that ST can be real when we do it well. Pascal and Judi taught us to type in a different way and it was a bit hard at first. I understand that it is important to look and be accurate. I hope I can type with less physical support, then all the skeptics will stop talking. Some people need to have it told to them over and over again. They are not hopeless. I think we can convince them...slowly. Many blocks make a bridge!

The Credential idea is about my need for connecting with other people and ensuring that they know I understand my options and can lead my own life. Close Aroha friends are empowered to carry out my wishes at times when I may be too unwell to communicate. We hope others may take up the idea of linked events like ours in their communities and regions. We might also have online events using programs like Zoom. It is good to learn from one another.

We have compiled a fuller record of Our Communication Matters! After a brief introduction in Part 1, Part 2 (pp.4-5) outlines skills training that can help to lessen a communicator's physical dependence on a facilitator. Part 3 (pp.6-11) explores theoretical and research questions as a basis for proposing ways to have people's communication taken seriously. There are some links to separate files.

Our Communication Matters!

Bridges-Over-Barriers

Guelph, August 12-14, 2019

PART 1: INTRODUCTION: WHAT IS TYPING TO COMMUNICATE?

Facilitated Communication Training (FCT) aka Supported Typing (ST), Typing to Talk, or Typing to Communicate, has since 1990 given voice to some people who live with severe movement and sensory disorders that prevent them from speaking and even make it difficult to point. We are concerned as the Bridges-Over-Barriers communicators who use Supported Typing (our preferred term).

Supported Typing or FCT et al. is a form of Augmentative or Alternative Communication (AAC) in which some persons with disabilities that prevent reliable spoken communication can express themselves by pointing to pictures, letters or objects or by typing or writing. FCT involves a communication partner (facilitator) who provides emotional encouragement, communication support (monitoring that the communicator is looking at the keyboard and checking for typos) and various forms of physical support (especially slowing and stabilizing the communicator's movements). But the facilitator does not move or guide the communicator to point to letters. Rather the opposite: the facilitator provides backward resistance, pulling the hand away from the device between each pointing or letter so the communicator has to be very deliberate in choosing the next letter.

This form of AAC, when first developed in Melbourne Australia by children with Cerebral Palsy (CP), was given the name Facilitated Communication Training (FCT), meaning skills that can be learned. With practice a communicator can type with reduced physical support or even no physical contact though emotional encouragement is still important. Some communicators have also developed speech along with the typing.

Two (among many) recent video vignettes are good examples of successful ST/FCT See Google details of full videos.

(a) Tim Chan in Melbourne Australia typing with mother, 2011,
<https://www.youtube.com/watch?v=Woy-XzC-UVs> 0.4-5.25 mins

(b) "Deej" Savarese in US Midwest, 2017. https://www.youtube.com/watch?v=E_DlFvdnbc c2minute youtube trailer.

Important questions:

- Why is Typing to Communicate so threatening? To some specific groups, such as professionals, social planners, service managers, even families and communities? Opponents seem to have a deeply rooted presumption that non-speaking people are incompetent and don't think or feel? Are we setting higher standards for people with Autism and Cerebral Palsy (CP) than for others?
- What can we do to convince people that FCT/ST may be the only reliable mode of self-expression for some who are voiceless because of movement and sensory differences? Why are FCT and positive communication services needed? Why are they so rare? Resources are scarce and expectations low for communication by voiceless people with ASD. How to make a difference?

We addressed these and other questions by considering both practice and theory.

- Our visiting communication mentor and Master Trainer Pascal Cheng with Judi Henry, Trainer of Trainers, coached Bridges members in various techniques to support greater physical independence and accuracy. (Tuesday morning by AB, all Wednesday by three other members of the Bridges group). Much of this part of the gathering was in the form of experiential learning and practice which we outline in Part 2.
- Our philosopher friend David DeVidi spoke to theoretical and research questions as a basis for proposing approaches to have people's communication via ST taken seriously. We introduced the idea of earning communication credentials based on good technique and practice. (Monday evening, Tuesday afternoon and Tuesday evening, Wednesday afternoon). These ideas are presented in Part 3.

PART 2: USING BEST PRACTICES TO LESSEN OUR PHYSICAL DEPENDENCE:

The original name of "FC" was Facilitated Communication Training, recognizing that people with quite severe movement and sensory disorders can train themselves to control their body movements to gradually do with less physical support from someone else like a facilitator. It's not easy or comfortable and takes a lot of mental energy to coordinate our body and brain. But we really want to try this. We need to ensure that it is our voice coming through in making decisions about our lives. If we can lessen our dependence on others, it could help to stop the skeptics putting us down for the most reliable way we can communicate.

Our work with Pascal and our facilitators was practical and experiential. It fits well with the discussions of ideas led by Dave and reported in Part 3.

All four Bridges members appreciated the time with Pascal and want to keep going with these practices. We will work on making some new videos to help others understand how the new practices look and feel. But you can get a fair idea by viewing the video taken of Pascal, some supporters and me working together in July 2015:

<https://youtu.be/3bP7jICJ4Ng>

A. Assessment to Determine Candidacy for Using Facilitated Communication *(shared by Pascal Cheng of the Howard Center in Burlington Vermont, July 2019, who assessed three potential young adults while here)*

“In order for facilitated communication training to be considered and successfully implemented, two things must occur: an individual needs to be identified as a candidate and those who support that individual need to show commitment to the training process. Both of these elements begin with the assessment.....”

You may request a copy of the full 2-page statement for personal/family use.

B. Communicator Skills –*checklist from Pascal Cheng, August 2019.*

1. Isolates index finger for pointing and maintains extension of finger
2. Looks directly at the communication board or device before and while pointing.
3. Maintains a stable and upright position while pointing or typing.
4. Resets hand/arm to a neutral position after making a selection.
5. Maintains smooth, even pointing movement with good muscle tone while pointing, e.g., not tense or floppy.
6. Maintains a deliberate rhythm which allows for accurate and/or reliable pointing or typing.
7. Consistently hits the target accurately without overshooting or hitting to the right or left.
8. Stays focused on message without going into patterns of perseverative or impulsive responding, e.g. hitting the same letter over and over, typing automatic words, etc.
9. Communicates clear messages consistently.
10. Clarifies unclear messages.
11. Uses punctuation, space and delete keys on boards and devices.
12. Uses device auditory and visual feedback to monitor communication and is able to self-correct errors.
13. Has a protest strategy to let facilitators know when they feel they are being influenced in their responses.
14. Can communicate for a variety of purposes, e.g. making requests, sharing information, participating in conversation, expressing an opinion, etc.
15. Initiates own topics for conversation or changes direction of conversation without prompting.
16. Points independently to a single picture, letter or word.
17. Types familiar, routine words, e.g. name, independently.
18. Types spontaneous messages independently.
19. Can indicate the need to communicate when sitting next to facilitator, e.g. lifts up pointing hand, reaches for device, etc.
20. When not sitting next to their facilitator, can let them know the need to communicate by getting communication device out, retrieving device, or using words or gestures to indicate need to communicate.
21. Communicates information unknown to their facilitator – message passing.

RATING SCALE:

1= Beginning level: Rarely demonstrates skill or needs intensive support to perform skill

2= Intermediate level: Demonstrates skill some of the time with moderate support

3= Advanced level: Consistently demonstrates skill with minimal support

NA= Not working on right now.

C: Mapping Out Your Road to Independent Communication. *Slide set by Pascal Cheng, August 2019.* 35 slides. You may request a pdf copy of the full slide set for personal/family use.

Independence-Aug2019-PC.pdf

Begins: Independent communication is:

1. Accessing communication aids and devices without physical support;
2. Initiating communication;
3. Being an equal partner in a conversation.....

PART 3: VALIDATING SUPPORTED TYPING/FACILITATED COMMUNICATION

12 Aug 2019: Monday evening:

The Right to Communication and Supported Typing: The Controversy, the Science, and the Potential.

Dave spoke to his slide sequence: **Communication-ST-dd-20190812.pdf**

Abstract: In law and in practice, there is growing recognition that *communication* is a basic right. We can see this in practice when translators are provided in court and ASL (American Sign Language) interpreters are seen on TV, and assistive technologies are made available to students in schools. People by now are familiar with methods that we can think of as *translating* messages that someone must communicate in some non-standard way into a form that more of us are familiar with.

But in general people are much less willing to accept methods like Supported Typing (ST, also known as Facilitated Communication) where another human being plays a very active role in a person getting their thoughts out of their heads. (Slides 2-5) It is common to see claims that ST is a scam, or a product of heartbroken people wanting to believe in miracles by believing that their previously uncommunicative loved one suddenly has come out of their shell. This is obviously a problem for people who rely on ST to make and communicate important decisions about their own lives, and those of us who care about them. A particular challenge is when the time comes to have people in positions of power—doctors, bankers, lawyers, judges, or politicians, for instance—take seriously what is being communicated (or what has been communicated) by someone via ST.

Why is it so hard to get acceptance for ST/FC? Why such vehement hostility, such harsh language? [Others present reported their surprise at these attitudes.] We considered reasons for skeptical and negative attitudes to FC/ST, including the reasons people say “the science shows ST doesn’t work.” We look at the actual state of the science which helped us zero in on what needs to be done to make ST effective and reliable for those who need it.

A closer look at the actual state of the science shows **problems with the design of early test studies** that came up with negative results (Slide 6). Well designed research on the other hand (Slide 7) has produced positive results when communicators have had a chance to develop FC skills, are given opportunities to practice tasks that mean something to them, and work with experienced facilitators in familiar surroundings. **Multiple sources of evidence from lexical analysis, eye gaze studies and qualitative research methods (Slide 8) support the hypothesis that some voiceless people can reliably communicate thoughts and feelings.** A shift in the conversation has been proposed (Slide 9) to start with the usefulness and validity of FC/ST for particular individuals, by asking these questions:

- **Is Typing to Communicate a useful and reliable communication/teaching strategy for this person?**

- **How can Typing to Communicate help individuals develop more reliable and independent communication?**
- **Is this a valid access method for people with disabilities who do not speak reliably?**

We do not say that everyone with ASD or CP should use FC/ST. But if other methods don't work in producing meaningful communication and the person continues agitated and unhappy, and especially if the person has movement and sensory disorders, it's worth a good series of tries.

13 Aug 2019: Tuesday afternoon:

Recognition and Rights:

A FAB Discussion about how to have my priorities and decisions respected.

I report this in the first person. Dave shaped this section but most words are mine. FAB means Friends of Andrew Bloomfield, my Aroha entity of close friends who have pledged to encourage and speak up for me.

Dave's Abstract: I use Supported Typing when making important decisions, both as a method to discuss their implications with people close to me and to communicate what I am thinking and, ultimately, what I have decided. Supported Typing is controversial, and likely to remain so. It is therefore important for I, and my family and supporters think through how to have my decisions respected. Later we can generalize from me.

Clearly, we're not going to be able to resolve the scientific controversy by showing that ST is a *generally reliable* method of communication — we don't have the resources, and I need things to happen now, not many years from now. Fortunately, the case that ST is an effective and reliable method *for some people, when done well* is much easier to establish. A better question for us to start with is how we can assure people (including ourselves) that

- ST is an effective method of communication for Person X, provided
- These conditions A,B,C are in place

The members of FAB are all convinced that ST works for me. We will use that as a starting point, and a resource to clarify our thinking. By asking *what it is that has made it so clear to us* that people hear my voice when I do ST, we will generate ideas for what we might use more systematically, both to show that *others* should take my writing as seriously as we do, and as the sorts of evidence that others might do to prove the same things about people they care about.

What makes it clear to my close friends that I use ST to express my own thoughts and feelings?

- Message passing is consistently successful when properly supported by trained facilitators who usually don't know the details of my life that I type about.
- I use ST mainly for what I call "critical" (rather than "casual") conversations when I choose topics and issues, with discussants or interlocutors who are different from my facilitators. Some of these are remote and connected by online programs like Zoom.
- I have my own idiosyncratic language—words, metaphors, turns of phrase that are unique to me and different from the language of my facilitators or my interlocutors. I may correct them on factual matters and am alert to any sense that I may be inadvertently influenced by my facilitator. I will stop typing and correct the words I did not choose.
- I am consistent over time in stated priorities and values; I may elaborate them but do not change them.
- I clearly remember people, events, values and joys from the past that are not known to my facilitators.
- I am motivated in my communication to shape my future and consistent in expressing the help I want from my close friends (e.g., in my FAB Aroha) in any contingency or emergency.
- While I am highly sensitive to stimuli and sometimes apt to be agitated and distracted, I am so grateful for communication support that I will remain calmly in an interaction for 2-3 hours, even when I am unwell. I often declare that access to ST has changed my life for the better.

Family and close friends in my Aroha believe in my abilities to understand my options and priorities and to make decisions about matters affecting my quality of life. They signed a Supported Decision-Making Agreement with me in

January 2013, endorsing my communication abilities and including provision for a Ulysses Clause by which I can entrust my designated friends to act for me in specific ways if I should be too unwell in some health emergency.

I continue to communicate my wishes for my good life, especially into a future beyond my parents. In planning for this we are aware that people in positions of authority over those who live with disabilities may need help to understand when our communication is reliable.

With my close supporters, I have come up with suggestions for documenting a person's ability to communicate wishes, ideas and feelings reliably:

a) Keeping records of conversations, compositions, even test results, and compiling a **portfolio or dossier of evidence** of the skills and capabilities to communicate reliably.

b) Drawing up a summary document that that says a person is qualified to communicate reliably when supported by an experienced facilitator (several could be named) and in settings which are conducive to best practice. I like the idea that these documents could be called **communication credentials**.

More general discussion prompted these suggestions of what could be included in a Communication Skills Dossier for others besides me

- **Evidence of particular communication skills**, and the degree to which a person has been able to demonstrate them, and under what circumstances. See also the **Skills Checklist in Part 2**.
 - **Reliable "message passing"**. (Examples: at home, with facilitation/support from person Y, the communicator has reliably provided accurate information about things the facilitator did not know about ... all the time, typically, sometimes ...)
 - **Degree of "communication independence"**: what sorts of supports does the person normally need to communicate successfully, and does it vary under different circumstances (e.g. is different report required in more stressful environments?)
 - Video evidence might be very useful here?
 - **Types of successful social interaction**: (could include Bridges participation?)
 - **Consistency of expressed opinion over time and with a variety of communication supporters**.
 - **Consistency of written communication to independent evidence** (e.g. written preferences match preferences known about in other ways)
- **Possibly document improvement/changes in communication skills over time**
- **Letters of reference from people who know the person's communication to be reliable in certain circumstances?**
- The communicator should be involved in deciding, for instance, what topics they are interested in being asked about when skills are being developed and measured.

Is there value in some sort of summary of this communication evidence? (that might be called "Communication Credentials")?

- Who would we use it to convince?
- Who "certifies" that it is true?
- Is it problematic to call it a "credential," since we don't ask most people to establish that they "clear a bar" before claiming something that it is their right to expect (e.g. to have what they say recognized as their own opinion)? But isn't it a premise of our discussion that people who use ST et al. are usually denied the rights to be believed on the basis of superficial observation and poor science? The bar is already set too high for them?

.....

13 Aug: Tuesday evening,

Ideas about Documenting Communication Skills

Dave's discussion document: Is there value in a process where individuals who use Supported Typing to communicate, perhaps in combination with particular facilitators, are "credentialed" as reliable communicators? This session was a discussion of this rich and complex topic, using the ideas generated in the Tuesday afternoon session as a starting point.

Imagining how we might develop the skills inventory and certificate/credentials:

A Bridges Over Barriers Communication Skills Certificate/Inventory might include content patterned somewhat like the items below (with items that don't apply deleted, of course).

Bridges Over Barriers Communication Cooperative Communication Inventory

This is to certify that [Person X] has consistently demonstrated the following communication skills, and that the Bridges Over Barriers Cooperative has seen and accepted strong evidence of the skills as reported below.

Reliably conveys accurate information (including information not known to their communication support person)

- Always/almost always/more often than not
- In familiar surroundings/in various surroundings
- With the following communication supporters: X,Y,Z
- With the following sorts of support [Verbal encouragement, touching on shoulder, resistance against wrist, whatever ...]

On important matters, **always/consistently/usually expresses the same opinions with a variety of communication partners** (including X,Y,Z ...)

Always/almost always/more often than not **expresses preferences and opinion ns in written form that match those that can be verified by independent means.** Etc.....

For information on the sorts of information Bridges Over Barriers relies on to support each of these claims, and how they are verified, see our website: [Of course, who does the verification work and how remains to be figured out ... what would it cost, how would it be sustained, etc.]

Discussion of these ideas raised the following points:

- While we think first of the communicator earning Credentials, facilitators who have proved themselves could also earn Credentials to support specific communicators. Note the Wellspring Guild of facilitators in the US which supports something similar as part of its community of practice. <https://www.wellspringguild.org>
- A Credential document should include a summary statement of why this person does not speak and why he needs support with the multi-tasking requirements of combining thought with physical movement.
- A Credential document should also note any fluctuations, ups and downs, in a person's health and well-being which require them to make "in case" decisions for how they are to be supported when incapable (sometimes called a Ulysses clause)
- Bridges-Over-Barriers might facilitate the process of credentialing communicators.
- Earning Credentials is an individual goal and entirely voluntary.
- The goal of earning Credentials could be an incentive to individuals to train and practice techniques to lessen physical dependence.
- Credentials could be revised to take account of increasing or decreasing skill levels, using Pascal's checklist. See Part 2.
- The existence of a Credential should signal the need for special consideration in any encounters with police, justice system, bankers, credit managers, lawyers, physicians, agency managers, government funding officials.

- A simplified Credential could be useful in some encounters with members of the public and form the basis of spontaneous interactions with community people.
- Collect evidence of how authorities including courts handle communication by non-speaking people?
- A Portfolio or Dossier would contain evidence of a communicator’s capabilities, incl any or all of:
 - Letters of reference with evidence of understanding options and making consistent decisions, e.g. personal physician, other professionals.
 - Dated transcripts of what individual has typed on various topics relating to life choices and quality of life.
 - Legal documents such as a Will or formal agreement.
 - Videos of specific dates and topics.
 - Certificates and diplomas relating to communication and decision-making.

14 Aug Wednesday afternoon part of Bridges gathering.

**A summary proposal to the Bridges group:
Documenting Communication Skills**

The suggestion is that having a record of evidence of a person’s communication skills — including information like what sorts of circumstances, who provides support, and so on — can be practically useful. For instance, it might be helpful when it is important to convince someone that what someone says via supported typing (or however they communicate) is a good reflection of what they are really thinking.

We imagine the record in two parts.

1. A **portfolio (or dossier)** that gathers together relevant evidence of different skills.
2. Since the portfolio might be too lengthy to share in many circumstances, a **Skills Inventory**, which summarizes what the evidence shows about the person’s communication skills.

We also suggest that having people not directly involved (so, not the communicator, not one of the communication facilitators, and not a family member) attest to the accuracy of the inventory.

Questions (with ideas from Tuesday night):

1. Are we right to think that this could be valuable?
 - Simply working towards documenting these skills is an incentive to improve your skills, so there will be indirect benefits, too?
2. What “infrastructure” would need to be in place to make it possible for people to
 - a. Develop their communication skills?
 - b. Compile the evidence?
 - Many people will need support figuring out how to document their skills
 - There need to be many qualified communication facilitators if it is going to be possible for more people to demonstrate some skills (e.g. the same messages being communicated with various partners)
 - Video seems like a compelling way to provide evidence of the degree of independent typing, so access to recording equipment, filmmakers would be helpful
3. Who does the “attesting” and how do we make sure it’s taken seriously?
 - It may help to also pursue things like having people who communicated by typing involved in self-advocacy organizations ... advocating for communication rights, but also other rights. As people typing to communicate get “normalized,” people will be readier to say “of course, I’ve seen that before” when they hear of someone else who communicates this way.

AB typed this document