

CANADIAN JOURNAL OF

Disability Studies

Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association
Association Canadienne des Études sur l'Incapacité

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca
cjdseditor@uwaterloo.ca

What Everyone Yearns For: The Ontario Story of Bridges-Over-Barriers

Andrew Bloomfield, Guelph, Ontario

For more than half my life (I will be 44 this year) I had no reliable way to tell others what was in my mind. I live with complex autism and cannot speak with my voice. People assumed that my intelligence was very limited, so I was never taught reading or math at school. I was lucky in my parents and twin sister, but away from home I felt excluded and isolated. In 1991 I was introduced to a way of communicating in which I am supported physically and emotionally to talk by typing. I have been able to use this other voice more regularly since 2000 and it has transformed my life. Feeling so good about myself, I was able to take the lead in forming a special support group with others who type to talk and want more control over their lives. We call ourselves Bridges-Over-Barriers.

Why are Supported Typing (S-T) and Bridges-Over-Barriers important? What was it like, not being able to rely on our voices? How has S-T changed my life? What kinds of barriers need to be bridged? How could Bridges help more people? I can comment from my own experience of trying to communicate and being misunderstood until I found S-T when I was 23. Being able to express my thoughts and feelings helped me to survive some very hard years. Forming the Bridges communication group has given me great joy. I hope that people will want to use S-T when they hear I have done good things as a result of communicating my ideas. More than anything else, I want people to understand the importance of having a voice and being heard.

I could not speak with my voice after I was about 5. I had to hope that those who cared about me would see what I was thinking in my eyes and behaviour. I could usually see and feel other people's thoughts. So I assumed they should know what was in my mind. I have learned more recently that this does not work for most people. When I was little, I was lucky that I could watch my sister leading the way. I would follow her cues. Having V as my twin was a big bridge.

How I learned to read is an interesting question. At school they gave up teaching me to read. I see now it was because I couldn't talk. I don't think they appreciated how much I wanted to and could learn. Long before I started school my parents read to us and V pointed to the words so I read whole short words. At school some of it sunk in but I could not read out loud to show them. I learned a bit from circle time and puzzles and Sesame Street type books. At home I remember loving the dictionary because it was full of words and pictures. It was a clue to others that I was smart. I fell in love with reading and words. I liked *Fortune* magazine because that was what G read. It was very grown up--the words were big and interesting. I could not read lines but words jumped off the page and I knew some of what it was about. Not really but it challenged me.

From age six, I learned the signs for many words in Signed English, more than one thousand. I got the idea that signing could help me so I really worked at it. I have a very good memory and my teachers called me their sign dictionary. Most of the sign vocabulary was for labeling pictures of foods or objects like various animals, or for making Yes/No choices. But several things prevented sign from being reliable for me to express myself. I often needed to give more complex answers than just one word, or to say "maybe" or "later" rather than simply "yes" or "no". It was also hard for me to initiate an appropriate sign. I needed someone to prompt me. I

would respond if someone said “What is the sign for ____?” I could easily learn and remember the signs, but it was different to take the lead in using them. I knew the sign but didn’t realize everyone wanted me to use it. I didn’t understand that back and forth communication was the point. “Toilet” and “No” were the first words I signed when I meant them. The other difficulty is that very few people know any sign language. I still use signs as a quiet way of telling my family that I need, for example, to visit the bathroom or to have a break or a rest. I still use some greeting signs but few people notice.

For nine years from age 12, I was at a special school for teenagers with autism. It was far away so I came home only at weekends. Too many of us lived close together. At first I admired the teachers who knew I needed intellectual stimulation. Later the classroom was a place where I acted from my gut. I did not get much there. It seemed that everyone looked at our behaviour more than our minds and communication. I think my mind was less engaged and so I acted out more. I also became more sensitive to many irritants in my environment though we did not understand all this till later.

In my mid-teens adolescent rage kicked in. I think this was because of sexual arousal and frustration and my wanting to be liked and admired and known to be smart. My anxieties grew and people drew away from me because they were afraid to set me off. Maybe I pulled away from people more than they avoided me. I could not explain this in words. I needed to run. I would start clapping my hands and shrieking and a staff person would point me out the door to the back driveway. What else could they do? At first I thought they were kicking me out but I came to feel relief. It was usually just an explosion as I reached the end of my coping. I was like

an avalanche starter. A loud explosion can set off an avalanche. My noise could make another student turn and hit or bite someone else. I know other students were also bothered by the crowded and noisy room but I couldn't really communicate with them or maybe we could have tried to demonstrate!

What it's like to be me

29 Jan 2003

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.
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.

Because I could not talk and had no way to express myself except through "acting out", nobody really knew how smart I was. It felt like I was observing my own life but not controlling it. I was sad and at times frustrated if I needed to say something. People may have cared but they didn't understand. This continued after I turned 21, had to move on, and was offered a place in a new group home that was much farther from my home. I really tried to be good for the first eight months. But I ran out of coping strategies and broke down. They put me on an antidepressant drug to which I had bad reactions. It wasn't explained to me then what to expect but I got very

agitated and hyper. It was supposed to be taken in very small doses. But with me the dose was increased when at first it didn't work. It had the opposite effect from what was intended. I was lost. It was a whirlwind. My mind was on fast forward. I was out of control. My body was not listening to my mind. Worse than ever in my life. My nervous system was moving too fast to even think. I had rage outbursts and meltdowns and my appetite was out of control. I had to struggle with my body every day. I might be either frozen and stuck or hyperactive and sleepless. The worst things were feeling my body is not part of me, seeing myself from outside, my thoughts not from my head. My family rescued me after five months of this torture, when I was almost 23. The drugs affected me for months after I stopped taking any and I could not control my body's reactions. I worried I would never be better. I was in turmoil. My inside was conflicted. The intelligent brain and the out of control body.

It was at this low point that I met the kind of Augmentative and Alternative Communication (AAC) that works for me, what we now call Supported Typing. I remember the first time I used S-T, when I typed to talk for the first time in words that made sense. That day I was jumping and shrieking but somehow heard M offering it to me. I typed my new dog's name, where I was born and where my grandparents lived, and had a conversation about an article in the *National Geographic*. I knew I could spell and was thrilled M had a way to stabilize me. It was another new bridge. I met many times with my friend H who is a communication specialist and with other friends who learned how to support my typing. I think doing it over and over gave me confidence and opened up my mind each time. I was astounded that I could finally express the sophistication of my thoughts. It is exciting to recall that part. I was upset that I was so out of control but relieved they did not blame me.

I was locked before S-T. When others did not understand me, I was sad and frustrated and agitated all the time. I got angry. I was hopeless. I never expected to find a better way. I knew I could spell and read. But I had no way to show it. A few intuitive people looked inside and past my autism. I was surprised by S-T. It was so liberating. I think S-T was the best bridge, and the people who helped me learn to traverse it have been M to H to V to E to B and J, accompanying me and creating new bridges. Even the synapses of my brain were new bridges.

Believing in me

4 Apr 2012

It cannot be understated
how much I need you to believe in me.
My wiring can detect it
if you have doubts
and if you have reservations.
I know what it means to get bad vibes
and I get bad vibes
if you doubt my abilities,
if you doubt I am the author
of my words.

I need you to believe in me,
or I might lose faith in myself.
I need you to send me
messages of encouragement
so I can keep up my mental state.
I will try not to disappoint you,
I will try to show you who I am.
But believe in me
and I have a better chance to do so.

Through professional friends I was able to get communication devices such as Canon, Epson, DynaWrite and LightWriter. These had voice synthesizers, so I and others could hear me speaking through the computer voices. It has always been very important to me to have a device

with a voice. I liked feeling important, a real working person with computers and new technology. I met people from other countries and showed them how I communicated. Some professionals visited from Zimbabwe. I liked them; they were open and gentle and encouraging. I was not nervous as they believed in my abilities. H invited me to show my communication to Special Education teachers in a summer course in Hamilton. I remember being very excited with some agitation but V anchored me with her presence as she touched my arm sometimes and spoke calmly to me. I typed a statement I had composed in advance and also answered questions from the teachers. My message was “Teach autistic children to read! They are smart!” I had no trouble answering but after a while felt overwhelmed and asked for a break. I knew H and V were so proud and relieved. My bridges in this experience were the chance to be a teacher for the first time and having people believe I could do it. My out-of-control body might have been a barrier, but my family and H gave me a chance.

It’s just as well that my family and closest friends were already supporting my typing from the early 1990s. Some terrible things happened. I became a temporary weekday resident of an institution which was the only thing anyone could suggest for me while I was still in such turmoil. But the staff did not know how to manage me and gave me more drugs. I came home for long weekends when I could use S-T and also went on wonderful trips with my sister. I told my family and friends that medication was bad as it scrambled my brain and we were able to prove that I should not be given drugs. Like other people who found their voices in the early 1990s, I was shocked by the backlash against S-T, or Facilitated Communicating as it was then known. Speech-language professionals and staff of agencies and boards of education were all forbidden

to use it. Then in early 1996 my sister was killed in a road accident. That was devastating for us all but led my family and friends to help me shape a new life for myself.

Supported Typing has been a key bridge in the good life and the many other bridges I have been building since 1996. I was able to say that my whole life must have:

- My own home shared with people I choose, so I am never trapped in an institution or group home again;
- Deliberate structure, planned days, some predictability;
- Reliable ways to communicate my wants and needs, interact with others, and make choices about everything;
- Friends of various ages, circumstances and interests, who understand, believe in and help me;
- An interesting and balanced life of learning and real work;
- Exercise outdoors and relaxation indoors;
- Caring for my home, garden and dogs;
- Keeping informed, being a good citizen, contributing to my community, and caring about the planet;
- Health care including my special diet and sensory integration strategies;
- My soul--music, prayer and meditation; and
- Some kind of safety net for the future.

Thanks to my family and friends, I have all these good things now. My own home, bought for me by my parents and held in trust for my lifetime by Guelph Services for the Autistic, is the

base for the other good elements.¹ My parents and our network of friends and advocates helped me to get some individualized funds which can be used for what I most need. The first few years in my own home helped me get used to having a life centred on my needs and strengths. A big part of the plan is that I choose the people who share my home and support me. These were all new ideas. I continue to grow in understanding my choices and responsibilities. I am so glad to be in my own home. I have felt proud and grown up and not impeded by others.

Regular support to communicate from March 2000 has helped me to comment on my life, refine my goals and make key choices. I was happy to meet B again as I had known her in my teens. She was not part of an organization or agency, so nobody could stop her using S-T. It was not easy to get going at first. B encouraged and believed in me but I got overwhelmed by my senses and doubted my abilities. I recall running away a great deal, and going to the washroom often. I also shrieked and covered my ears and got stuck and could not type or hold B's hand. I needed someone by my side to help me develop as a communicator and a thinker. As I typed when we had been meeting for only a month, "A really good facilitator tries to feel everything that I feel. She does the supporting, and pulling back of my hand. I do the moving, pointing, spelling." Meeting every other week for a couple of hours, B and I have persevered with typing to talk for the past twelve years. Even on hard days, S-T can unlock my frozen body and bridge the gap between stuck and silent and fluid and articulate. I compose and type my own words, but it is part of the dance of my life with my facilitator.

¹ *Creating a Home and Good Life of My Own: The roles of a housing trust*. Edited by Elizabeth & Gerald Bloomfield. (Guelph Services for the Autistic, 2012). Chapter 2 is called "Listening to the Person", about supported decision-making.

Being introduced to a way to communicate deeper thoughts, I began to develop as a person.

Before S-T, people might know basically what I wanted or if I was upset. But nobody knew my thoughts. S-T was like being admitted to a university and the more I typed the more my brain power grew. I knew I was smarter than they all assumed. But I had no experience with higher thought, world issues, and advocating for myself and others. Two barriers were: first, not having a way to express higher thoughts, and second, not using my brain to its fullest until I had a way to express myself. I have grown intellectually and emotionally with S-T. I interact more, I hear about others' thoughts more now and I am less in my own head. My language skills have developed and I am learning more about how the world works.

Once my abilities were revealed, people gave me more input and materials to grow with. I tell my supporters that I want to learn more about various topics. They get me books and films and we search the Internet to find more. I love to copy-type from these materials and learn through several senses. I do this without physical support on desktop and laptop computers using WriteOutloud software. I read the material with my eyes. I feel its meaning as I touch the keys to type, and I listen to the computer voice saying it back, word by word, sentence by sentence. This is one of my favourite activities. I can copy-type for hours at a time, just with my dog and music for company. I also type social stories and plans in this way. It is interesting that I can copy-type without physical support, but need it when I am composing my own thoughts.

Supported Typing helped me to tell people my basic needs and choices but also my deeper thoughts and fears. In 2000 my life plan was unfolding well. But in some sessions with B I typed

about my nightmares of worrying about how my life would be supported and what would become of me after my parents:

I am terrified when night comes and I fear that I will be left alone. The thing I am scared about is seeing the day my parents die. I believe that we must get things moving. I really want to feel secure, to know who will live here. I need to make and keep friends. How can I find friends to share interests, spend time with me, and not depend so much on G and E? I'm concerned about my future security. I need to know my means of support. I need to know that there is a safety system.

My parents and friends were glad that I was able to express my fears and that I wanted to be more involved in planning for the future. We thought and talked about the qualities of people I need to support me and how my future could be more secure. We hosted some events for people from all over Ontario with presentations by the man who first thought up the microboard in Manitoba. We decided to go ahead and incorporate a small support organization like a microboard. As we could not use that word in Ontario, we thought of Aroha instead as the general name. It is an Aotearoa/New Zealand word meaning sustaining love, friendship, family, community and caring. For the particular name of my Aroha we chose Friends of Andrew Bloomfield (FAB for short). FAB is the core of my circle of friends and has special powers because it is legally incorporated.²

My Aroha is a creative way to keep up my good life as we have designed it for after G and E are gone. I am one director and so are G and E now. There are three other directors who are very

² For more about the functions of Aroha entities, see Sections B and D of *Creating a Home and Good Life of My Own: The roles of a housing trust* (2012), and this webpage: <http://www.uoguelph.ca/oaar/aroha.shtml>

good friends of various ages, talents and life experiences. They are the core members of my circle of friends and can call on others to help in the future. I feel good knowing about my Aroha. I know my future is more secure. I feel safer knowing that my Aroha would be in charge with me, not some strangers. I'm proud I am a pioneer. It's important that we have people in our life who are there because they want to be, not just because they need to be. I have the luxury to have this because my family and Aroha have supported me to make this happen. Only good people with good support and intentions make my life positive. Thank goodness for S-T and friends who listen to my words.

As I became more articulate, my passion for words came out as what my friends call poetry. B encouraged me. I was told to let the words flow and they did. I preferred short words but sometimes used just one long or complex word in a poem. A poem is like a song in my mind. My first four poems were set to music by a friend who now has a therapy centre in South Korea. They were "Old friends and new" inspired by the friend with whom I worked with horses, "What it's like to be me", "My Amy" for my companion dog, and "Spring". When I was 38, we published a collection of my first 38 poems, and 54 more poems form part of my autobiography in 2011.³

How do my poems emerge? Sometimes I have a thought that percolates for a long time in my mind. I'm thinking many ideas at once. It is sometimes too much because I feel ready to explode with ideas and can't hear them all at the same time. When I get my next chance I just open up my mind and the words come pouring out. I like to tell my thoughts in a story. Some call it a poem. I

³ *In My Mind: thoughts and words of Andrew Bloomfield, 2000-2006* (Guelph: Caribou Imprints, 2006); *Bridges over barriers in my life with autism* (Guelph: Friends of Andrew Bloomfield and Guelph Services for the Autistic, 2011).

call it my life. Poems are an expression of my thoughts. I always had thoughts but just couldn't express them. I was always happy with my life, but locked inside with too many ideas. People knew AB on the outside but not the man inside. I now let people know and I feel content. I get the computer to speak my poem back to me, and I decide on a title. Almost always I like a poem the way it is and make no changes. Occasionally I may change just one word. For now I am not interested in fitting my words to a format like a haiku or sonnet. I don't like rhyming at the ends of lines as I find it alters my meaning.

My life as a poet

21 Mar 2012

Our lives go in circles,
over and under bridges.
We may have a plan
but the path is never straight.

My life as a poet began
before I knew it was my journey.
I collected ideas
and snippets of this and that,
stored in my brain.
I did not know,
in the days my voice was not heard
that one day I could say it all--
say it in ways that sounded
pleasing to my ear
and to the ears of others.

Now the words come easily
although my hand is not yet stable
and I need the support of poetic partners
who know how to hold my reins
without stopping me in my poetic path.

I do not know
where this all will take me.
Will I lose the poetry
if I gain the strength to type alone?
I do know I need you now and always.
You are part of my life as a poet.

In the early years of S-T my mind was more black and white and I thought more literally. Since 2000 all my typing and talking to others have made me less rigid in my thinking. Now my mind feels it is overflowing with ideas and images full of colour. I see a kind of aura around the word for an idea or the name of a person. Until I was regularly communicating with S-T, I did not know that this interests others. I have ideas for paintings too. So far I find it easier to express my idea of a painting in words than to achieve the painting with brush and paints. I wish there could be some way of stabilizing my arm and body so I could paint more of what is in my mind.

Bridges-Over-Barriers happened when I was ready for it. I was confident that my way of communicating was reliable, both to make clear my choices and any worries and to express my personality and ideas in poems that get people's attention. Once my own life was flowing smoothly, I was able to think about others who need to express themselves and be understood.

Bridges-Over-Barriers is a community of communicators. We are adults who cannot speak with our own voices and use alternative methods to express our thoughts and feelings. We meet monthly in Guelph for day gatherings which I host. We started informally when two Toronto friends with their supporters came by train on 4 January 2004 to visit me. They both already used Supported Typing (S-T) with my communication facilitator B. I had no other friends who typed to talk so it was exciting. I loved the experience of talking with others but it wasn't easy. I was running around a lot. L was rearranging things and M bit himself at times. There may have been more visits to the bathroom than actual talk. I was less nervous than them since it was my home.

I did not then imagine that we would one day have Bridges-Over-Barriers. But I suggested that we tell other families about getting together to share our thoughts and feelings.

People got to hear about us and seven months after the first gathering, we were up to seven communicators. Two more came from the Greater Toronto Area, one from Lambton County, and another from the Detroit area across the US border. Over the following years, new members have joined us from downtown Toronto, Norfolk and Haldimand counties, Waterloo, Barrie and Peterborough. Some members have since moved too far away to attend our gatherings—to New Mexico, Nova Scotia and France for example.

We were all nervous and excited and impulsive at first. As the group got bigger, people went in and out, paced and made noises. But we also typed our thoughts. We all understand what it's like to have autism and movement disorders and to cope with changes and new places and people. We feel for one another in being stuck or hyper or compulsive. I'm in constant motion and my mind's always going. We had to get used to one another and our idiosyncrasies. My motivation was great to keep focused and not let my obsessions take over. We all lose it sometimes in different ways. My friends should not worry if they lose it when we are together. I have to control myself if others lose it. But I don't want them to feel bad.

Our gatherings are planned in ways that help us all to stay calm. I email an agenda and questions in advance for our discussions about anything from spirituality to special diets. We plan a good structure for the day, with communication sessions morning and afternoon. Quiet music and a cool room help. Hiking and a lunch break are really important too, so there is a time to move and

eat. We view and discuss videos on topics important to us and share our interests in music, painting, our experience of nature and plants, and our concerns about life transitions. We are thankful for everyone who makes our gatherings possible. Our parents, friends, facilitators and support workers bring us to Guelph and provide us with the physical and emotional support to express ourselves. They are patient and supportive; they believe in us and build our confidence. We have two experienced communication facilitators to encourage and mentor us on techniques. Sometimes there may be more than 30 at our gatherings. As our numbers became too large for my living room, we now meet mainly at the Ignatius Jesuit Centre of Guelph. We use a calm and beautiful room for our conversations and go for hikes in the extensive grounds.

We the communicators shape the flow of discussion and are the main talkers. Our supporters talk very little. We have grown close. I enjoy our gatherings more than almost anything else. It is exhilarating having a group of real friends, because we can really share and connect. We plan questions with time for us to think about them in advance. We keep a record of what people say unless it is private. We type about our good news, hopes and fears. There is time to mention difficulties we may be having in our lives. We have talked about being autistic, obsessions and lack of control, and making friends. We prove that autistics can have feelings for others and stay focused for a long time. The ideas and words are ours and not the facilitators'. The gatherings are made for us and give us support and a safe environment to talk. At lunch the facilitators, family members and supporters can add their thoughts and share news and resources.

Bridges-Over-Barriers became our name in mid-2005 when I suggested "bridges not barriers" and B added "how about 'over' barriers?" A bridge was my image of how S-T can connect my

island to the mainland society and overcome my frustrations in being misunderstood and not in control of my life. Bridges is a very special support group. We are all quite different in our personalities and circumstances but very similar in how we communicate and see the world. I am grateful for all my friends. I need them as much as they need me. They always think I am so special. But they are the ones who bring new ideas each time to build our bridge stronger. We share what is important to us and I always learn something interesting from the meetings. I think that everyone tries very hard to be caring and respectful of one another.

Groups like ours are rare because we have been assumed not to have thoughts or feelings. We have not been educated or encouraged to express our thoughts. Once we are adults, people may think we have no hope of growing our minds and showing our intelligence. Bridges is special too as we invite and welcome people to come to us; we cannot wait forever for the community to think of including us. We know of only one other group in the world like ours—The Brotherhood of the Wordless in South-East Queensland, Australia--and one of its members actually visited us in Guelph in 2007.⁴

Guests and observers are welcome at Bridges gatherings: we ask them to come with open minds and to observe our “protocol”. We need a calm quiet atmosphere to focus on thinking and typing. It may be a problem if observers come and make discouraging remarks without listening to us. This matters because we autistics have no filters, and so are bombarded by all kinds of stimuli through our senses including negative energy from others.

Our message to people who would like to be guests at our gatherings:

⁴ The Brotherhood of the Wordless produced a DVD and book, *Tapping on the Heart of the World* in 2005. <http://www.brotherhoodofthewordless.com.au/index.php?pageid=4455>

Bridges-Over-Barriers is a support group that has been created by us as we grow as communicators. We live with autism and movement difficulties and gather to share communication skills, technology ideas, life planning, friendship and community. 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.

Bridges-Over-Barriers has become my passion and a gift I can contribute to the world. It is clear to me that Bridges should grow so that more people can express their thoughts and control their own lives. I know I have to keep speaking up for our communication rights and for reliable ways we can develop our own voices. We need resources to pay for training communication facilitators and assistants and to match them with people who want help to develop their voices. Everyone should understand how we need the people in our lives to support us to express ourselves and to listen and pay attention to what we say.

This is how I first appealed to friends for help in 2005:

I want to tell you about an idea. I am an autistic man. I don't speak with my voice, but I have a voice to express in a different way. A friend supports me to communicate. We want to start a centre to help others the way she helps me. But it is not possible to do

this in the world of agencies that we have now. There isn't enough money to help people like us. We need support to communicate which helps us improve our lives.

When I learned how to communicate in a new way, when I learned to use Supported Typing, I had a whole new world open. I knew I could think and was smart. I had no way to tell anyone except my eyes and behaviour. I was angry, frustrated and worried a lot. Now I have a way of communicating and, though I am still autistic, life is better.

We want to open people's minds. We want to build bridges, not walls. We want people to see, hear and understand how much communication means to us. Supported Typing is very hard. It strains our bodies and minds. But it is all we have. So it is good to do it and we are glad we can.

My friends on the board of Guelph Services for the Autistic (GSA) agreed to shelter our Bridges activities and to administer funds from donations. When I asked them, my friends and family made generous donations instead of giving me presents. People also gave to Bridges in memory of family members who have died. We have helped several new communicators to get started. We have paid for people to attend workshops and training sessions. We have spoken up about S-T or other AAC modes for people who may be vulnerable because they cannot use their voices—through newsletters, support for training and networking, and special events.

Producing our Bridges book and video is our biggest project so far.⁵ The video shows us sharing ideas in our own words and explaining how important communication rights, Supported Typing and our Bridges group are to us all. It begins with these eloquent words of KV:

Bridges connect people and places. They allow ideas to flow and worlds to expand. Without bridges we would be isolated, voiceless and lonely. We would be uninformed and ignorant. Bridges take many forms. They can be large, small, simple or sophisticated. Bridges have served us since early times. They are beautiful and wonderful. Bridges-Over-Barriers is our link to freedom and life, transporting us over the barriers of being ignored, overlooked, misunderstood and underestimated.

In the video we discuss what it's like to live with movement and sensory differences and other symptoms of autism and our need for friends who listen, understand, accept and include us. We sum up the messages we hope viewers will get from our film. We want people to see our joy in communicating with others and that we are strong at listening, understanding and being ourselves. We want to be recognized as intelligent, sensitive and spiritual people with thoughts of our own. We need to be allowed to make our own choices and are keen to learn and try new things, especially in lifelong education and recreation. Please assume we are intelligent, help us to express ourselves, and listen!

A three-minute-long, subtitled clip from the video can be seen [here](#).

Our video shows how we share our thoughts and feelings. Being able to talk with others who use S-T helps me talk more about how I feel about myself. We need conversations with people who

⁵ *Bridges-Over-Barriers: In Our Own Words*, book edited by Andrew Bloomfield, and DVD with same title produced with videographer Christine Zorn, Guelph 2010. Bridges has a webpage at <http://www.ont-autism.uoguelph.ca/bridges.shtml>

understand why S-T is important and how we mentor and encourage one another to keep trying new things even when it's uncomfortable. We have a place to talk things through and work out the ideas together. Bridges-Over-Barriers is important to keep everyone communicating. We break some stereotypes about our empathy: we very much like to sit and talk and be together, even though people think we are not social. Bridges has also got the attention of other people in my life: they listen and understand me better because I am not the only person who uses S-T. I am one of many intelligent and interesting people who are sharing their ideas and lives. I have friends and a mission in life. It is worthwhile for all of us to find a purpose, not just about ourselves, to focus on.

Our book, also *In Our Own Words*, has the same purposes as the video but a larger scope. More of our conversations are quoted. One was a question-and-answer discussion with our friend Martha Leary on "What it's like to live with autism: understanding our movement differences" (Chapter 3).⁶ Chapter 4 is about our senses which may be more or less acute than other people's. As KV says, "My awareness of everything is excruciatingly present at all times...I even feel vibrations in the air and changes in the weather. I pick up other people's moods and sometimes feel quite crazy. I get anxious over things that seem trivial to others... I tune things out as best I can, but nothing is ever single-focused...I focus best on one sense at a time."

Chapter 5 reflects our experience of sharing struggles and strategies to improve our lives. The complex challenges caused by the movement and sensory differences in our brains and bodies

⁶ Martha is a Speech Language Pathologist whom some of us have known for nearly 40 years. Some of her work on neuromotor differences is reported in: A. Donnellan, D. Hill, & M. Leary (2010) "Rethinking Autism: Implications of sensory and movement differences." *Disability Studies Quarterly*, 30, 1 (17 pp). Special issue on autism and neurodiversity, online at <http://www.dsqsds.org/article/view/1060/1225>

may be very painful and are always there, even when we seem calm. What can hurt even more are the ways people may not listen to us or understand our difficulties, abilities and dreams. Facing change or transitions is hard for us anyway, and harder if nobody takes time to explain what is going on or to ask for our thoughts and listen to us. We can feel very frustrated by these barriers in the way of relating to other people or living our everyday lives. This chapter includes some thoughts about a sense of security in our lives, the qualities we need in families and friends, and our wish for more choice and control in directing our own lives.

Our book also addresses some problems in showing people that our way of communicating works for us. Chapter 2 is about our need to express ourselves and our rights to be heard. It is perfectly clear to me that S-T can be a reliable way of communicating for people whose movement differences do not let them speak with their voices. But some people are opposed to S-T (especially when it is called Facilitated Communicating). That matters if such people are in positions of authority and can prevent autistic people from getting communication support. It seems to us that this opposition is based on several misunderstandings.

First, there has been a negative assumption that people with full-blown autism are so hopelessly impaired in their intelligence and feelings that they could not possibly think, let alone learn to read, spell and type. “Autism” has been a doom-laden word, especially if you were classified as “non-verbal” or “low-functioning”. Professionals tended to focus on what was wrong and not look for or encourage our abilities. Some of us endured many years of feeling hopeless. If we didn’t talk by age 5, there was no hope for us. We were dumb in every sense. As early as 1984, Dr Anne Donnellan proposed the principle of the “presumption of competence” as the “least

dangerous assumption” but it has not yet reached everyone who needs to understand.⁷ It is encouraging that Dr Pat Mirenda, an influential professional in the field in Canada, has shifted her position on supporting AAC for people with autism to what she calls a “back door approach”. She writes:

... we need to question what we think we know about people with ASD in general and how we support those individuals whose speech does not develop to communicate through AAC in particular. I think we need to do this because there is a growing body of science that suggests that we might have gotten it wrong, at least some of the time, for some individuals. I think that it is not okay to get it wrong for even one person; when we talk about communication, we are talking about peoples' lives, no less than that – so there really are no degrees of freedom. If we get it wrong, if we miss the boat – people drown.⁸

Second, people may not perceive that it is really we who are doing the “talking”. It is our thoughts that we are typing, and not our assistant’s or facilitator’s. Even our allies and friends, if they have not actually taken part in S-T, may have some reservations about our way of communicating. This goes back to the earlier 1990s, when the enthusiastic adoption of “FC”

⁷ A. Donnellan (1984) "The Criterion of the Least Dangerous Assumption" *Behavioral Disorders*, v9 n2 p141-50 Feb 1984. Chapter 2 in *In Our Own Words* mentions some movements for disability rights that have helped to shift attitudes to people who cannot use their vocal chords. The Autism National Committee (AUTCOM) has been the only autism advocacy organization to consistently declare support for “FC” as part of its dedication to "Social Justice for All Citizens with Autism" and its commitment to positive approaches. Its policy is “that everyone has something to say and a right to say it”. With its journal, *The Communicator*, AUTCOM is dedicated to “protecting and advancing the human rights and civil rights of all persons with Autism, including access to state-of-the-art communication options for all with unique communicative and social needs”. Other organizations that have advocated for communication rights include TASH, the Nancy Lurie Marks Foundation, and ISAAC, the International Society for AAC. In Canada, Augmentative Communication Community Partnerships-Canada (ACCPC) is a federal, non-profit organization that undertakes social innovation projects to promote awareness, justice, enhanced quality of life and community participation for people who use AAC. It is devoted to implementing communication rights in our communities.

⁸ P. Mirenda, “A Back Door Approach to Autism and AAC”, *Augmentative and Alternative Communication* Vol 24, Issue 3, September 2008, pp. 220-234.

provoked a backlash. Perhaps in the first enthusiasm for “FC” not enough attention was given to basic techniques and best practices by facilitators or to working out a theory to explain why “FC” worked so well with at least some people with autism. Some sceptics would not believe that people with autism could think or had language or anything meaningful to say. They used blind research methods to test the competence of communicators and show that the facilitator, perhaps unconsciously, was the real author of the message. Chapter 2 of *In Our Own Words* says more about research on both sides of this question.⁹ In studies with positive outcomes it was found to be critical that communicators have prior practice sessions in message passing (where a person reveals information that others can verify but which was not known to the facilitator). So the communicators know in advance the rules of the experiment and are not taken by surprise.

Professionals and policy makers may still refuse to consider S-T because it is not “evidence based”. I think that evidence is found in different places. If it lies under a rock and you don’t look there, you won’t find it. I look inside the words and I look at what is happening. How can I sit and type for two hours when sitting still is so hard for me? Could we all sit together in a gathering if S-T is not real for us? I think if you look at some of the messages and our interesting uniqueness they are also evidence. Our gatherings and DVD show us calmly and quietly sitting together, taking turns to “speak” and listen to one another’s words. Books, films and videos of other communicators reinforce that message. We are inspired by some people trained with FC/S-

⁹ For a survey of FC and validation tests in the mid-1990s, see *Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy* by D. Biklen and D.N. Cardinal (New York: Teachers College Press, Columbia University, 1997). A current review is by C. Ashby, “Whose “Voice” is it Anyway?: Giving Voice and Qualitative Research Involving Individuals that Type to Communicate”, *Disability Studies Quarterly* Vol 31, No 4 (2011) <http://dsq-sds.org/article/view/1723/1771> The Institute of Communication and Inclusion at Syracuse University supports continuing research projects:

http://soe.syr.edu/centers_institutes/institute_communication_inclusion/Research/recent_projects.aspx

This is a bibliography of written and video material about FC Training and Supported Typing:

<http://www.annemcdonaldcentre.org.au/facilitated-communication-training-select-bibliography>

T who have persevered to become virtually independent typers and even develop limited powers of speech.¹⁰ People could also learn from quite sophisticated research findings. For example, the EASIEST research project at the University of Padua in Italy used textual analysis to find that communicators usually had a richer vocabulary and more complex sentence structure than their facilitators or assistants and that it's not likely they were influenced by their facilitators in what they say or how they say it.¹¹

There are many myths about autism and our way of communicating. One myth is that Supported Typing (what we used to call FC) is easy. It is not! But it is all we have.... And it can transform our lives.¹²

¹⁰ Early books by successful communicators were *Beyond the Silence: My Life, the World and Autism* (2000) by Tito Rajarshi Mukhopadhyay of India and *Lucy's Story* (2001) by Lucy Blackman of Australia. North American success stories in film include Jamie Burke in *Inside the Edge: A Journey to Using Speech Through Typing* (2002), Sue Rubin in *Autism is a World* (a 2004 Academy Award nominee) and Larry Bissonnette in *My Classic Life as an Artist* (2005). These communicators are also featured in the volume *Autism and the Myth of the Person Alone* (New York University Press, 2005) which includes essays by them as well as their conversations with Douglas Biklen as editor. The other two are Richard Attfield of England and Alberto Frugone of Italy. Among other books and films by successful communicators, Kevin Vasey a Bridges member co-authored *The Road Trip: Life with Autism* (2005) with his mother, Gloria Pearson-Vasey. The 2011 film *Wretches and Jabberers* features Larry Bissonnette and Tracy Thresher traveling to Sri Lanka, Japan and Finland for conferences that include conversations with communicators in those countries.

¹¹ For one of three reports see: http://cdn.intechopen.com/pdfs/20051/InTech-statistical_analysis_of_textual_data_from_corpora_of_written_communication_new_results_from_an_italian_interdisciplinary_research_program_easiest.pdf Statistical Analysis of Textual Data from Corpora of Written Communication – New Results from an Italian Interdisciplinary Research Program (EASIEST). Lorenzo Bernardi and Arjuna Tuzzi in *A Comprehensive Book on Autism Spectrum Disorders*. ISBN 978-953-307-494-8 Edited by: Mohammad-Reza Mohammadi. Publisher: InTech, September 2011.

¹² As Rosemary Crossley, says: "Facilitation is a last resort...Facilitated communication is difficult, limiting, time-consuming, and controversial... the worst possible way to communicate. If you can't make any other way work, though, it's being *recalled to life*." Dr Crossley was first to develop the practice and theory of facilitated communication, mainly for people with cerebral palsy, before it became known in North America after 1990. An early notable success was featured in Crossley's book with Anne McDonald, *Annie's Coming Out* (1980), also made into a film in 1984. She published *Speechless* (E.P. Dutton, New York) in 1997 and for many years has directed the DEAL Communication Centre in Victoria, working with people who have Severe Communication Impairment (little or no functional speech), and dedicated to "Breaking the Silence" and a world in which everyone who cannot speak has the means and the opportunity to communicate." The DEAL Centre was recently renamed in honour of Anne McDonald who died at age 49 in October 2010. See:

<http://www.annemcdonaldcentre.org.au/facilitated-communication-training-select-bibliography>
http://members.optusnet.com.au/~dealcc/DEALPages/DEAL_Facilitated_Communication_Training.html

I have been asked for advice about starting a new communication support group like Bridges. A good way is to build a group of S-T users in a region, with some smaller meetings of say three communicators first to feel comfortable. Plan communication time, food and a walk. Have a list of questions to help people ahead of time to prepare if they want. You could show our Bridges DVD and another time the *Wretches and Jabberers* film. Gradually add new communicators with their family members and other supporters. You also need good hosts to plan all the practical side of a gathering. People should share respect for one another, so ask guests and observers to agree on something like our Bridges protocol.

Supported Typing is not easy for either communicator or facilitator. Everyone needs to share positive attitudes and techniques. Here are some tips I have learned for myself and in the Bridges group, and from valuable guides by experts in the field.¹³

- Observers and assistants in training must understand how a good facilitator provides explanation and emotional support to a person being invited to communicate. I tell my friends that emotional support, believing in me, is the single most important factor.
- The technique of backward resistance always surprises a new communication assistant and can persuade them that S-T is real. I need to have my hand raised from the keyboard between each letter so I have a second to decide the next letter or character. Then I bring my index finger

¹³ We recommend these resources, in addition to the references in previous notes:
A Slice of My Life: Facilitated Communication Training (2009) by Jane Remington- Gurney who directed the Options Communication Training and Therapy Centre in Queensland Australia since 1998:
<http://www.optionsetc.com.au>
Everyone Communicates!: The Augmentative or Alternative communication (AAC) Resource, with information and connections maintained by Judy Bailey at <http://www.everyonecommunicates.org>

down to the key I intend. Once I get fluent in a session, I may not need to have my typing hand raised as high from the keyboard. But I take my assistant's supporting hand to the key: I am not guided there by the assistant.

- Statements by the communicator that seem odd or out of character should be verified. If I say something surprising or have got myself into a nonsense phrase, my assistant says "Do you really mean that?" and I will backspace and correct if necessary. But I can also really mean something that surprises or amazes my companions. In the early years of S-T a few communicators seemed to accuse people in their lives of abuse and this led to public controversy and opposition to "FC". Some of these statements were found to be true. But some statements that seemed like allegations were found not true. Before anyone is accused of anything, the communicator should have more conversations, perhaps with different facilitators, to confirm or correct what he or she seemed to say.

- People supporting or observing us may doubt us when we do not keep our eyes glued to the board. They need to know that we have peripheral vision, so can usually see the keyboard or screen even when we are not looking at it all the time. It's hard for our sensory systems to keep looking continuously at anything: eye contact with another person is difficult for most people with autism. We also memorize the keyboard layout. However I know that people feel surer of what I am typing if I look at the keyboard and the monitor, so I try to do that for them.

- When beginning an S-T relationship, it's good to practice often for short periods and to plan very simple conversations with predictable words—like names and activities we are sharing. So

a new supporter can focus on feeling the physical relationship rather than trying to understand unexpected ideas or comments. A communicator probably senses the diffidence of a new assistant and may hold back from saying much until the relationship is comfortable.

- As communicators and facilitators become more experienced, less physical support may be needed. When beginning S-T, a communicator might need very firm support under the closed fist with the index finger pointing. When rapport is well established, a communicator may need only the lightest touch of a finger under the wrist, or a touch at the elbow or shoulder, or no actual touch at all, just the presence of a familiar facilitator. Even with long experience of S-T, however, we may need more support at times when we are feeling anxious or upset or typing on a difficult subject. The film *Wretches and Jabberers* illustrates this. Though Larry and Tracy are very experienced communicators and know their facilitators well, they are unobtrusively supported by touch in stressful interactions or topics.

- Music and rhythm may help communication to become more fluent. I always like to have classical music playing while I type. Some people are helped by a soft drum beat or a ticking metronome. Some very experienced typers who didn't previously use their vocal chords have started to say out loud the words they are typing, when helped by music or rhythm.

- We are all individuals and may need different kinds of support. I tend to be rather tense and vigorous. Sometimes I like to be supported by the use of a perch or small wooden rod, my assistant holding one end of that to stabilize me and so not actually touching my hand or arm.

Sometimes, when we have got going in a conversation, my assistant can unobtrusively reduce the amount of physical support.

- I feel a bit wary about communication devices that are too small or primarily use picture icons for people to click on. iPads and iPods are being promoted as an easy option for people with autism. But these could tend to limit people to labeling or Yes/No choices. I think there could be research to see if the new devices help people to be more or less expressive. We should have the option to express ourselves in words and open-ended sentences.

- In an ideal world everyone would live with communication assistants for ever at all times! It's important to get used to communicating with new people. I need at least two levels of supported communication:

- a) simple everyday interactions about how I am feeling and choices among options with various assistants, and

- b) more occasional deep thoughtful conversations when I set the agenda of topics I choose with experienced facilitators who provide all the support I need to get my words out. I do not want to lose this kind of deep support.

It is good to have a comfortable relationship with at least two experienced assistants in S-T and preferably more.

Supported Typing gave me my voice at last. Typing to talk has enabled me to make choices about everything that affects me and so transform my life. People in my life have a chance to understand me as I am, not as some stereotype, and so allow me to be wholly me.

Bridges-Over-Barriers has given me a great sense of purpose as well as true friends and allies. People who cannot speak with their voices because of autism deserve to be heard and to use whatever way works for them. Sharing our way of communicating, the barriers we struggle against, and the strategies we work out are ties that bind us as a special kind of family.

We want to open people's minds to the possibility that S-T really allows us to express ourselves and that presuming our intelligence and respecting our efforts is the least dangerous assumption. We need to persuade professionals and policy makers, as well as families and friends, so they will provide opportunities for more of the thousands of adults and young people who do not yet have reliable ways to communicate and be heard. New communicators need good support with S-T. We want to find, motivate and train new communication assistants.

Since mid-2005, I have dreamed of a Bridges-Over-Barriers centre to make connections and help others to find their voices. I see it as both a safe refuge and a kind of power house for communication and life planning--a resource for various Ontario communication groups and a place for retreats and training workshops. We can share what we have learned. We will offer more communication training and practice for assistants so that new communicators can get going. Our words will be heard once we give people hope. We need more value given to Supported Typing.

Always hopeful, I composed this solidarity anthem and a friend has set it to music. We the Bridges communicators are all going to try to sing it together in 2012!

Song of Hope for Bridges

3 Nov 2010

We are many and we are one:
The bridges that connect us are
our minds and our bodies that
others sometimes find hard to accept.

Together we find acceptance.
Together we find hope.
Together we find community.

We are many and we are one:
The bridges that connect us are
our words and our feelings
though they flow from our fingertips
and not our lips.

Together we find acceptance.
Together we find hope.
Together we find community.

We are many and we are one:
The bridges that connect us are
our family and friends who facilitate
our interactions with each other and the world.

Together we are acceptance.
Together we are hope.
Together we are community.

References

Portrait of Andrew as a young man. Video of my life and plan, produced by Monica Carsience. Guelph, 1997.

About Myself: Portrait of Andrew who has autism. By Lucie Milne with the Bloomfield family. Guelph, 1998, revised edition 2003.

Listening to Andrew. Video about how I communicate, also featuring Martha Leary, Elizabeth Bell and Beth Komito-Gottlieb. Guelph, 2000.

“Loving people is loving God: Autism and spirituality”. Article with Andrew Foster in *The Presbyterian Record*, May 2005. <http://www.presbyterianrecord.ca/2005/05/01/loving-people-is-loving-god/>

“I am host in my home... I am whole and have hope.” Article by Elizabeth Bloomfield, published in Autism Ontario manual, *Living with ASD: adolescence and beyond*. 2006. Pp. 257-266.

In My Mind: thoughts and words of Andrew Bloomfield, 2000-2006. Guelph: Caribou Imprints for Bridges-Over-Barriers, 2006. Volume of 38 poems with some linking passages of my words.

Odyssey: ten years of a good whole life in my own home By Andrew Bloomfield. Guelph: Caribou Imprints for Bridges-Over-Barriers, 2008.

Bridges-Over-Barriers: In our own words. Book edited by Andrew Bloomfield and DVD produced with film maker Christine Zorn. Guelph: Guelph Services for the Autistic for Bridges-Over-Barriers, 2010. Book ISBN 978-0-9866586-1-7. DVD ISBN 978-0-9866586-0-0. <http://www.ont-autism.uoguelph.ca/Bridges-announce-1.pdf>

Bridges over barriers in my life with autism. By Andrew Bloomfield. Guelph: Friends of Andrew Bloomfield and Guelph Services for the Autistic for Bridges-Over-Barriers, 2011. 190 pages. ISBN 978-0-9866586-2-4 <http://www.ont-autism.uoguelph.ca/AB-2011-blurb.pdf>

Creating a Home and Good Life of My Own: the roles of a housing trust. By Elizabeth & Gerald Bloomfield. Guelph Services for the Autistic, 2012, 192p. ISBN 978-0-9866586-3-1 <http://www.ont-autism.uoguelph.ca/GSAmanual-blurb.pdf>

Bridges has a webpage at <http://www.ont-autism.uoguelph.ca/bridges.shtml> as part of the Ontario Adult Autism Research & Support Network (OAARSN) website created to support Guelph Services for the Autistic and its initiatives.

Inquiries about any of the items above may be addressed to Guelph Services for the Autistic, 16 Caribou Crescent, Guelph, ON N1E 1C9, Canada, or by email to ebloomfi@uoguelph.ca