

***What everyone yearns for:  
Really good support to communicate...***  
*By Andrew Bloomfield*

“Typing to talk” has enabled me to have a much better life. I need more supporters so I can choose and comment on priorities and sustain my good life into the future. I also want to help others who cannot speak with their voices to express their thoughts so that people listen, understand and respect them. That is the vision of my dream for Bridges over Barriers.

I have lived with quite severe symptoms of autism for almost all my 39 years. Since 30, I have also had occasional seizures and spells of pain and turmoil when I cannot control my body. But I am naturally the most exuberant person I know. I was introduced to supported typing (what we used to call Facilitated Communicating or FC) in 1991, when I was 23.

Though I seldom speak with my own voice, I like to use the simple words “talk”, “speak” and “say” for my communication through typing. The devices on which I type have voice synthesizers, so I and others hear me speaking through the computer voices. It has always been very important to me to have a device with a voice. I now use a DynaWrite for supported typing, while on my desktop computer I type without support in WriteOutloud software. I read and copy text independently and so learn new ideas and information. I take them in through my eyes, my fingertips and my ears. I feel good about typing independently: it exercises and stimulates my brain. But I still need physical support to “type to talk”—to compose and express my own inner thoughts. Who knows if my copy typing will lead to independent “typing to talk”?

Supported typing has brought me respect from others. Before I could type to talk, nobody really could know what I was thinking. I communicated as best I could by some signs and by pointing. But it was so limiting and unreliable. I was impeded by my movement disturbances. I could sign for things I needed, but I couldn’t say what I thought and felt.

When I was about 6, some experts thought I should learn Signed English rather than be taught to speak with my voice. I understood this might help me to be “heard”, so I worked very hard at signing. I learned about 2000 signs, so that my teachers called me the walking sign dictionary. However, it didn’t really go anywhere, because too few people in my life would sign, and also because the signs were mainly for basic needs and objects, rather than ideas. And then sign

went out of fashion. Later, I did not much like picture exchange cards, as they seemed demeaning. The pictures just showed objects, not thoughts.

Before supported typing, other people probably saw me as a primitive childlike person who was not a thinker. I know it must be hard to respect someone who paces and screeches, but says nothing intelligent. Some may assume that people who do not speak cannot think. People may have respected my dignity, but not my mind. I feel that, when I had a reliable way to type real thoughts, more respect came my way.

I would like people to know that I am trying to be in control of my body, even if it looks like I am sometimes not. When my body goes in the opposite way from the way I want, I must try to keep calm, even though I feel upset. From the outside, people only see my racing and pacing. Not my inner struggle. I hope that when I hold my ears, they can understand that I am really working to hold in the storm. It's not usually that my ears hurt. I may hurt somewhere or noise may get on my nerves. Supported typing lets me tell people when my body is acting up. I sometimes express my thoughts in poems, like this one:

What it's like to be me (*29 January 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.

I remember being a little boy and wondering why Vickie (my twin sister and best friend) was getting things that I didn't. I mean that she could do things while I was still thinking of doing them. One example is playing. I would want to join her, but could not move there until she had left off and moved to something new. My body was stuck. I was trying, but ended up running around and jumping. It became important for me that she could get things for us and talked for us both. It became

clear to me pretty early on that she was more in the world than I. I struggled to be in the world she was in.

Whenever I could, I looked to Vickie for a lead as to what I should do in a situation. I might not understand exactly what was happening or why we should do something. But I found it was better to follow her lead. She would look out for me. I remember that I learned about humour and irony by listening for the tones of voice when my parents and Vickie talked. I liked to join in the laughs and smiles. At school, when I did the right thing by copying what others did, my teachers would say "He's only cueing; he doesn't really understand." But that was the way I learned to cope.

From 1991, Vickie was my key facilitator with supported typing. We traveled to many places, before she died in an accident in 1996. I called Vickie my window to the community. I think of her every day. It is most painful around the time of her death. It is in my heart the times we shared.

I think that my parents knew I was more than I could express. They talked to me and tried to understand my ways of coping. I taught myself to read from about two, before school, reading books with Mum or Dad. Vickie and I would sit on either side, and follow the printed words as they were spoken. It felt like a world of mysterious words that I could enter. A favourite activity was to read through big dictionaries which had little pictures to go with the words. I still love to read the many books and magazines in my home.

But I have felt that others pitied me. Nobody can respect you if they pity you. At school my teachers expected so little of me. I might have learned more if they had respected my mind's potential. The Principle of Least Dangerous Assumption proposed by Dr Anne Donnellan in 1984 says that it is better to presume competence. This means that it is more dangerous to assume a person doesn't understand than to assume he does. If my teachers had understood the principle, they would have given me more opportunities than just doing easy puzzles and tying shoelaces.

Supported typing is so liberating. I was locked before it. I had to hope others would see in my eyes and behaviour, but these were not reliable. I saw that nobody really knew how smart I was, but I had no way to express myself. It felt like I was observing my own life but not controlling it. 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. A few people really looked inside and past my autism. Until supported typing, I did not know I thought in words that others could understand; I was just absorbing their words.

I remember the first time I used supported typing. It was with Martha. I remember trusting her and letting her show me pictures and ask questions. I pointed to and typed the right words. I spoke for the first time in words that made sense. I was very surprised by supported typing. Now I really knew I could spell and read, and other people saw it too. Now I had thoughts. Now I could talk. The thing everyone yearns for is really good support to communicate.

My life now is excellent. I have my own home and it revolves around me. I know everyone who comes here is friendly to me. My parents, my circle of friends and my housing trust listen to me and respect my choices. I am comfortable and safe here. My garden is heaven on earth. My dog Amy is my friendmaker. I'm happy with our progress. Well planned and not stressful. I grow into each step. All this is possible because I can talk through typing.

When I had been using supported typing occasionally for two years, a friend asked me to "speak" to a room full of special education teachers. Vickie drove me with my Epson communication device to Hamilton, and two of my friends were there too. My device had a voice, and the words I typed were also projected on to the wall for all to see. I had prepared things to say and also answered questions the teachers asked me. My main message to them was "Autistic children are smart: teach them to read."

For the past seven years, Beth has regularly visited my home for supported typing sessions when I can reflect on my life. She is a very good facilitator who gives me both physical and emotional support. I wish that others could have this kind of help. Since early 2004, I have hosted regular gatherings of other communicators. In May 2005, after seeing *Autism is a World*, I felt inspired to think of starting a place of refuge and organization for communication support and life planning for people who live with autism. I see Beth is an important part of the dream, and composed this poem:

I am dreaming of a place  
where we can come together,  
to be together,  
to communicate together.

I am dreaming of a place,  
where I can be a leader  
and a friend,  
a person who helps  
and a person who needs help.

I want to dream with you, my friend,

To build that bridge you told me about  
Because we both like bridges.

Dream with me  
And we will make that place I dream of  
And the bridge in your dreams.  
(8 June 2005).

We have named our communication group Bridges over Barriers. It is about building bridges, not walls. I love the image of a bridge--like that of a door or a window. Supported typing is not a “cure” for autism, as some enthusiastic people thought it might be. I am not interested in a “cure”. Supported typing is a bridge that takes me from my island to the mainland. I think I am visiting the mainland, not living there, and visiting is fine. My good friends and my dog Amy also bridge the gap between me and the rest of the world.

Our friends, when asked to support the dream of Bridges over Barriers, have been very generous. We now have some seed money and want to offer:

- Materials and events to make everyone aware of supported typing and deep listening, starting with family members and friends, so they know for sure that our communicators are speaking their thoughts
- Training for new facilitators or communication supporters
- More training for ourselves to become more independent typers and comfortable with new supporters
- Perhaps a conference with workshops, for everyone who cares about helping people who don't speak well to communicate in their own way.

I also dream of a special place of refuge and organization for communication and life planning.

=====

Andrew Bloomfield lives in his own home in Guelph, Ontario, Canada. He hosts regular gatherings of communicators in the group called Bridges over Barriers (webpage at <http://www.ont-autism.uoguelph.ca/Bridges-2007.html>). *In My Mind: Thoughts and Words of Andrew Bloomfield* was published in 2006.

*Andrew: Poems since "In My Mind"*

**My Battle (27 June 2007)**

I am moving out of the fog called ill-health;  
It feels like returning from a war zone.  
I listened in spite of the bombs in my head  
exploding;  
I heard my friend remind me to listen to my  
body;  
He shared the soldier's story of the battle  
within.  
He gave me the gift of telling me his tale,  
And I gained hope to control my own body,  
In the war of my health.

**Nice Weather (23 May 2007)**

When the weather is nice  
I feel my spirits  
soar like the birds.  
Like floating clouds  
I drift along

When the weather is nice,  
my own clouds clear.  
I hope for  
sunny days and cool nights,  
so I can feel nice weather  
inside and out

**BRIDGES (13 December 2006)**

I want to tell people  
that I love Bridges.

It gives me a focus  
and centre of interest,  
a cause that is important  
because I believe in myself  
and my friends.

I think the spiritual connection  
between us is hard to describe.  
I know I feel it.  
It is family and godly.  
I do think we get ideas from each other.  
Who knows where it begins,  
and where it ends?

**My Body Betrays Me (21 February 2007)**

Bodies please us,  
but not always,  
when we need them  
to move or sleep or talk.

Not always with movement,  
in ways I want to count on,  
am I able to be content  
with my body.

I tempt fate if I say I am well,  
because like the weather,  
it could change  
to a tornado in a moment.

Rushing over me,  
wind and hailstorm,  
my body swirling and moving,  
and not stopping for a breath.

**A Poem about Dads (13 December 2006)**

I think you know, my friend,  
that fathers are important.  
I know you know this is so.

You visit your father  
as he lies in his last days,  
and I think I can imagine  
you holding his hand.

You touch him, I know,  
in your company,  
and you touch, I hear,  
in lovingly caring for him.

He is the only father you have:  
our fathers cared for us,  
and we care for them,  
in the end.