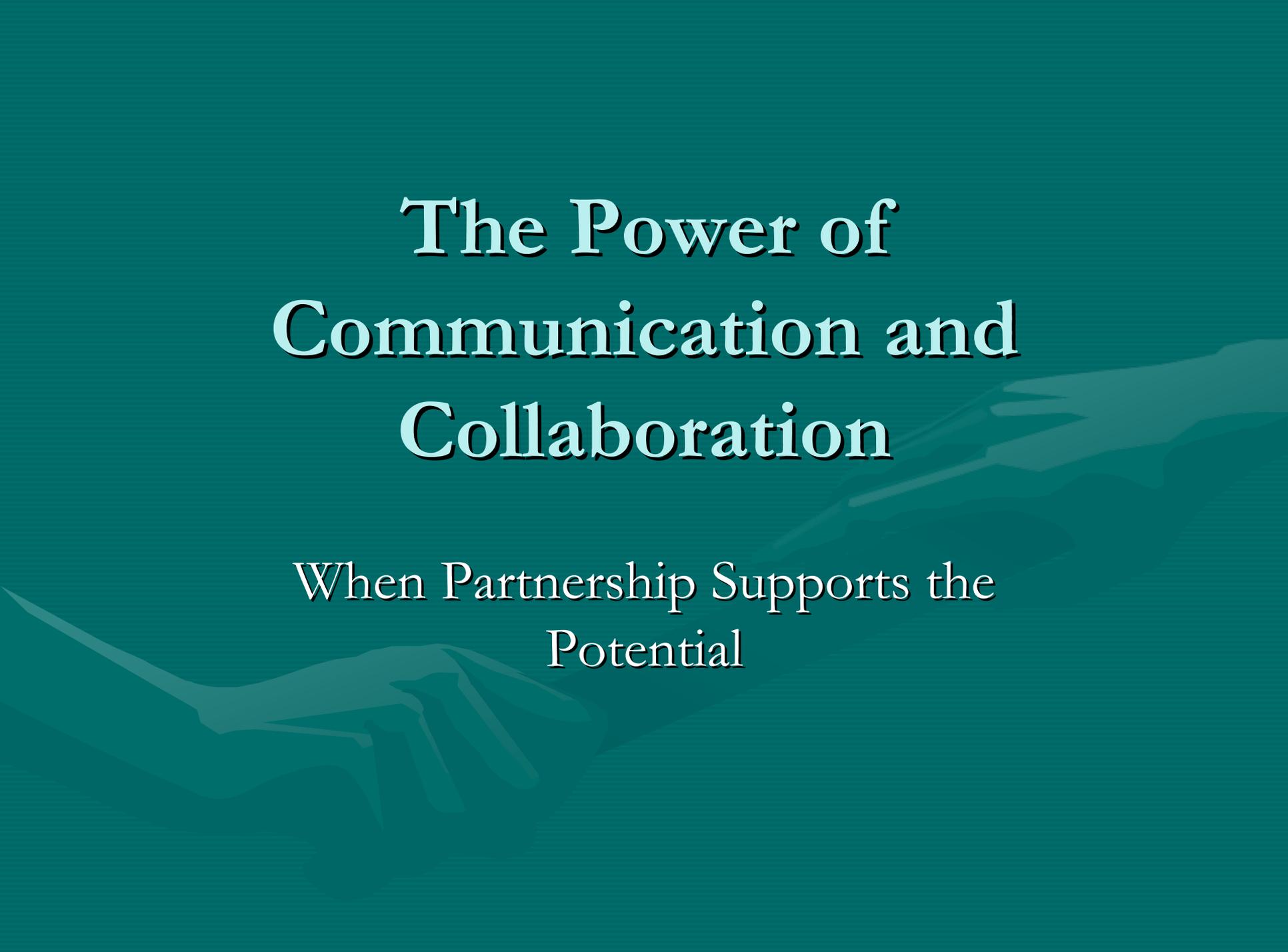


- **Narratives and Stories**
“Making Communication Happen”
Burlington, Vermont

Jamie Burke
October 26, 2010



The Power of Communication and Collaboration

When Partnership Supports the
Potential

“Don’t tell people what should be done, show them what CAN be done!”
I.M. Trunk



- Good afternoon, everyone. It's my simple joy to be here in Vermont with you, and to be asked to share some of my life's journey. Some here may know of my journey in the long road to being able to type to communicate, to move to greater independence within that, and to attempt the ability to speak.

- You may understand through watching “Wretches and Jabberers” that some of my festive friends here and I share a similar path through the use of typed communication.

- I want to say to you, I can only describe my own journey in living with autism, where life is a balance for me, straddling that gulf between what is desired, and what is. I would like to tell you about some of my thoughts, bundled together from the last 23 years of my life.

- Some of these are from my tender years, and some from experiences as my journey continues to unfold.
- I was given the understanding of autism when I was 3 years old. For me, autism means a system that is sensitive and finding life in extremely high resonance. As a child in my tender years, I could only just scream and try to talk,

- but since no language would transfer from brain to voice, I acted in a way that would make sure I was removed from areas that caused me distress. Not being able to communicate was terrifying, even though my brain held many joyous words in the files of memory. The difficult task was to move them from thought form to spoken form, but at that strong moment,

- my words of echoed form (echolalia) were the main and present format. I know most people believe that echoed speech has no function, but I must comment that all words spoken are of some use. I would repeat the same words spoken to me in the idea of a picture negative. It allowed me a second glance worth the time to process it correctly and try to understand it's meaning.

- It is so difficult, and my frustration was enormous, and attempting to sort through the maze of confusing sensory issues made me feel the easiest route was possibly to give up. Then came the anxiety, working as a large block to the letters and their connection to sound. I am curious, Tracy, Larry, and Chammi, and my other friends here, to know if this is your experience as well?

- The name place of my preschool in Syracuse is called the “Jowonio” school. In the language of the Haudenosaunee Native Americans, Jowonio is translated, “to set free”. I was a little boy with luck, because Jowonio was a joyous and inclusive place of community. The excellent person who opened doors to change and to challenge the old and ridiculous thoughts of disability, arrived

- with a wonderful and new method to assist in communicating. The man was Dr. Doug Biklen, and the method was Facilitated Communication and both became good friends to me. FC was suggested to my family to support my effort to experience it. I was a tender 4 years old, and facing the emotion of being able to communicate with what I saw as words in my brain.

- I was able to trust one or two people to help me struggle through the fear and meaning of what would now be expected of me. In the beginning of this journey, I could not process the simple structures of words, but could connect with much larger words and I desired to say them in my voice, but could only type them.

- There were enormous emotions for me, and perhaps fear of demonstrating what I carried inside. For many reasons both understood and misunderstood, I could not type much with my mom in the first early year of thought expression.

- She did become an excellent support. And perhaps now, I need to say that in learning to type, it is so much engaging the trust of the facilitator who must be confident in their support. They needed to make me feel less anxious and not more. It appears that is no simple task.

- Autism has been a creative lesson in life for me. My sensory systems seemed to be not matched between my brains requests and my body's agreement to perform the task. This is the motor planning ability that did not exist for me. Many people seem to not understand, that not being able to initiate movement, certainly does not mean that I do not desire that movement.

- This of course, affects not being able to speak, even though I can “see” all the language in my brain. I do not know if you can comprehend the anger and frustration that this brought to my soul, and how many times I would get actively upset.

- In my life, in order to be able to sit in class, useful accommodations were a constant support. In elementary school, beanbag seats, rocking chairs, headphones with music, net swings, and being squeezed between 2 mats in the physical therapy room, allowed me my upsets, but to never needing the request to leave the school. I have been in inclusive classrooms for all my public school journey.

- But mostly important, is that the people who formulated the circle of life there, presumed me to be competent and intelligent, even with a different way of demonstrating my intelligence and abilities. As I say these words to you, please understand well, I have had many days of struggling with this and there have been those who rejected my typing.

- However, the ones who I carried strength from are the most paramount and critical people, the ones who demonstrate the interest in understanding the potential power of possibilities. I believe you must see these possibilities as a shift of your experience systems, even if they are different from yours, and then see that potential as a true possibility.

Speaking on National Public Radio with Facilitated Communication 2010



- My friends here who live with autism, know the anxiety that autism brings and the fundamental reality that it can be overwhelming at times.

- In school, going to the gym was helpful, although the noise was painful to my hearing. I participated in Adaptive Physical Education, (APE) and that was helpful. At this time, I did Auditory Integration Therapy and that was helpful to calm my sensitive hearing and distinction of sounds. I also received a lot of Wilbarger Brushing and Joint Compression. I was allowed to chew gum and in most classes,

- to be able to get up and move my body. The cafeteria and playground were not the best places for me at that time. The issue of moving bodies was very hard to navigate and the swings were always the busiest choice for others. Middle school for me was difficult, and I get nervous when others think I act weird or different. I feel stronger when you get to know me and my autism. Your knowledge is my power.

- Middle school also brought another new facilitator. I was less comfortable with her expectations, but she was a taskmistress who helped me to become more independent. She assumed I could learn to retrieve my own books from my locker, arrange my materials in class, and attempt to initiate my desire for typing.

- I have to say it helps to have a gentle push, and not an overly excited shove to help your students or friends accomplish new skills, but please take time to consider the difficult process needed to shift between personalities.

- Certainly students like me struggle at times, but when we struggle, so many times I see the lowering of expectations. I desire you to know it is profoundly vital to not give up on the ideal to move us quietly through the door of opportunity, when there are those who may have their toe pressed against it.

- In middle school, friendships were slow to gain, and I ate lunch in the cafeteria alone many days. My sensory issues to smells were strong. My support person and a teacher figured out to order lunch for weeks ahead, to pay ahead, and then I was just able to get my tray fully loaded at the entrance, neglecting the ordeal of looking at and smelling all the many foods.

- I am greatly perplexed when I see young student's systems being overwhelmed when trying to be what is "normal" .

- I first thought this to be a failure, but I have failed many times and I learned failing is fundamental, but it is not an easy opportunity to learn from. My desire of heart and soul was in the yearning of being able to speak, and when I was 11 years old, I engaged the use of my new Lightwriter device.



- When I first went for my assistive technology evaluation with Marilyn Chadwick, my school staff would only sincerely support the purchase of a laptop. However, I knew the Lightwriter would be important to my journey. The screen was visually appealing to my eye. The lesson learned here, is to make certain that your choices are accepted as true and that you are listened to and valued for your suggestions.

- With the pleasing color of the green screen on the Lightwriter, and its voice to speak my typed words, my brain seemed to begin to initiate the patterning of access to connecting my voice to words. Reading my favorite video boxes was helpful. They were like family, always there and never changing. With the Lightwriter, I could both see the words and hear them in a constant voice that was always the same for me in speed and tone.

- When I was 12 years old, the process of the speaking pattern seemed stronger from using the Lightwriter, and I challenged the risk of saying just one word at first. After much practice with forming the sounds, I was able to turn the speech off on my Lightwriter. I really believe there are many others who can form this connection, even though the journey is long.

- I must also say that the therapies I do have been of an enormous support. Many of them help to cross my midline area, and that gives support to utilize both sides of my body. It gave me faster speed in doing typing with both hands, and helps me to organize my body when I cut food, eat, to shave and to wash my hair. I do the Samonas Listening Therapy still, and it helped with sound distinction and connection.

- I was given the opportunity to meet Suzanne Oliver, a neurological music therapist who hails from Arizona. I was assisted to learn how to use the drums and metronome and they surely formed a connection in how I connect the brain with my own initiation. I find I am more integrated in my situations.

Platform Swing



The Flo Bag



Neurological Drumming



- My public school gave me the opportunities to access these during my day. That helped me to sit in class and absorb information easier and to better manage my environment and to accommodate classroom difficulties. I am not planning a segregated life for myself and I believe we need to give our bodies the needed structures of support in order to live in the world today.

Breaking the Barriers Presentation Washington, D.C.



NY Senator Charles Schumer Announces, “Combating Autism Act”.



- In August, I was doing a presentation at Syracuse University that I titled, “Can Being a Ball Really Work in a Room Full of Squares?”. Well, I am here to say it can. I always say to school staff that good inclusion is the essence of a student’s success, and do not just give us the desk then leave us to only fill the seat. We are certainly worth your efforts.

- I am now a senior at Syracuse University in the College of Arts and Science. I am majoring in Religion and Society and my minor is Native American Studies. I would like to again engage my thought, that your knowledge is my power. My professors have a better understanding of my experiences when we can share communication meeting person to person.

- I tell them I may need to do stims in order to stay in class, and that it may be difficult for me to answer quickly. I need to say that all brains release information in different ways, different speeds, and in different complexity. But, it is still learned information. Really, I think simply my stims may help my management to absorb information at times.

- I need to explain that my anxiety may be a direct block for word retrieval for me, and can be a block to the strength of the process to listen.
- Sitting near natural light is helpful, and not in the middle of the crush of desks. The speed of the professor speaking and strength of voice pitch is always destined to be an issue to be dealt with for me.

- I utilize my texts on CD's in order to be able to see and hear information at the same time. Extra time for tests, and a separate room so I can read the exam out loud myself, and a large font size on tests are necessary for me.

- In science or biology classes and labs, having an electronic scale and a dual-eye microscope was helpful and taking lab exams on a separate time from other students.
- My anxiety effected my motor control in a strong way to working the microscope, so not having to make the others wait for me was beneficial.

Biology Lab



- My voice is moving to having more initiation to my speaking, but I must have access to my communication devices. Through typed communication, I demonstrate my knowledge. We need the freedom of opportunity to speak in any form that is needed, and I am angered at those who label these devices to communicate as an unnecessary right.

- It is important that we remember that using communication is really different than just yearning to engage in a choice. Communication devices are our expression of who we are attempting to be, what we can become, and are never to be obtained and then left in a bag in the closet.

- At Syracuse University, I have been truly fortunate with people who respect me and really try to help my success in life as a student. Passionate, creative ways are sometimes necessary, and I vitally feel this has been engaged.

Syracuse University Office of Disability Support Mr. Stephen Simon, Director



- With communication and intelligent support, friendship is a paramount reality. It is an attempt of life and love when we are sharing the simple agreement of connection. Please remember it seems we speak so much on the discourse of academic demonstration, but perhaps we must also realize the importance of offering the strength of human connection through shared communication.



- This is the journey I am on, from a boy in his tender years with no voice, to a boy who could begin to find his voice and formulate useful language. It has taken many, many people who presumed me to be competent and who held my dreams. My life may not be just as yours in your ease of speaking, but I love libraries, books, music and art, vintage silent movies and bike riding and walking in the natural world.



- Thank you for hearing my words and thoughts today from my heart and my experiences. My wish is for a world of acceptance and questions always answered, and times of peace for all.

