Typing to Communicate

Understanding Facilitated Communication

BY CHRISTI KASA-HENDRICKSON, PH.D.

"Individuality is something I was born with through having a disability. Even my typing makes me unique. Typing makes me the desirable fun girl in control of my individuality."
— Blair Brown, college student and FC user

"Typing felt like freedom from autism. Have you every felt trapped and ran outside and shouted Yes! That is how it felt for me."
— Jamie Burke, high school student and FC user

"Without FC I am imprisoned in a body that cannot reveal who I really am. This form of communication has changed my life and it is now full of possibilities and opportunities for me to be heard in the world."
— Tyler Fihe, college student and FC user

Blair Brown, Jamie Burke and Tyler Fihe have been typing to communicate since the early 1990s. All are young adults with autism who have difficulty using speech to communicate in an interactive and meaningful manner. As young children, Blair, Jamie and Tyler were introduced to a method of communication most commonly known as facilitated communication (FC).

Through many hours of practice, careful training and work with trained facilitators, they have learned to point to pictures, symbols, words and letters as a way to communicate their thoughts.

When Jamie was introduced to FC at the age of five, he began pointing to pictures, familiar words and symbols that represented activities in which he could engage at his preschool. His facilitator would place a gentle backward motion

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on his wrist and ask Jamie to point to his desired selection. As Jamie began to have success in making choices, his facilitator started a process called “fading support,” in which the facilitator physically supports the person at the wrist, then to the mid-arm, to the elbow, shoulder, etc. As Jamie worked to fade the support he needed to type, he also began to access letters on a small communication device.

Now, many years later and a senior in high school, Jamie types independently; his facilitator no longer needs to touch him as he types, but he continues to need the encouragement and direct support of a facilitator to focus his attention to the message, so he can continue to type assignments in school and messages to friends.

All three FC users have been in the process of fading the physical resistance provided by a facilitator over the past 10 to 12 years. FC has been highly successful for each in terms of communicating and expressing. But, as with many methods related to autism, FC comes with its share of controversies and difficulties in understanding just how it works.

The Nuts and Bolts of Facilitated Communication

Facilitated communication, or facilitated communication training (FCT), is a form of augmentative alternative communication (AAC) in which people develop pointing skills for communication using pictures, symbols, letters and words.

The goal of facilitated communication is for individuals to achieve independent typing, often with a combination of typing and speech (Crossley, 1994). People who use FC successfully often use it as part of a total communication approach. It is used in combination with other methods of communication, including speech, sign, gesture systems, etc. This enables the person access to the fullest range of communication options (Rossetti, 2005).

FC is helpful for those who cannot speak or whose speech is highly limited (e.g., echoed from others or limited to one or a few-word utterances), and for people who cannot point reliably due to neuromotor problems such as impulsivity, regulation of movement, poor eye/hand coordination, and difficulty with initiating and sustaining movement to develop effective pointing skills.

The method involves a communication partner, typically called a facilitator (e.g. teacher, speech pathologist, friend or parent) providing multiple methods of support that may include, but are not limited to the following:

1. Physical Support Physical support may include helping to isolate the index finger; stabilizing the arm to overcome tremor; applying backward resistance on the arm to slow the pace of pointing or to overcome impulsivity; touching the forearm, elbow or shoulder to help the person initiate typing; or pulling back on the arm or wrist to help the person not strike a target repetitively. The physical support does not involve guiding, leading or moving the person’s hand or arm.

FC users report that physical support is needed to initiate and sustain pointing, as well as to help regulate movements. “My impulse control problems, my way of going too hard at the letters and my problems with preservation, are things I need help with from my facilitators,” said FC user Tracy Thresher. “The facilitator must slow me down and pull my arm back to help me start again so I can point to the correct letter I am going for. I would not be able to type the words I really want without the firm resistance of the facilitator holding me back from typing automatic words.”

Often, physical support provides FC users with needed proprioceptive awareness (the sense of the position of parts of the body, relative to other, neighboring parts of the body). As FC user Tito Mukhopadhyay explained, “I could not point to objects for many reasons. One of the most important reasons is that I had very little sensation in my body. Touch is always a big help when an activity is new for me. Only through practice and through the gradual fading of the touch [can] the activity be done independently.” (Biklen, 2005)

As Jamie Burke was working on fading the need for physical support, his mother would often place a light touch on his shoulder or his back. According to Jamie, he needs a light touch because, “If mom does not touch me at all, I lose focus. I need a touch on the shoulder to remind me to keep going. I must try very hard to think and type independently, but I urge mom to keep on insisting I type independently because I like being independent.”

The physical support provided to FC users follows a dynamic trajectory rather than a linear formula. As the FC user receives physical resistance to the wrist, work toward fading that support begins. However, this fading process is impacted by several contextual and personal experiences. While becoming independent, there may be moments and situations where more support is needed.

For example, although Jamie can type independently in most situations, when he is tired or experiencing stress or increased anxiety, he may require some physical support at the shoulder or
at the back of the arm to continue typing his message. And when Blair Brown has a new facilitator, there will be a period of time when she receives more support than was previously needed from facilitators with whom she had been working for a longer time. Further, when Tyler Fihe’s facilitator observes that he is experiencing fatigue and slowing down, she might provide some physical touch at the elbow until he shows signs of resuming his stamina and then she immediately will fade the support.

The fading of physical support is present in the training process as someone is introduced to and uses FC. Although there are many FC users who no longer require physical support when typing, the majority of the time emotional and communicative support is needed to engage in conversation and schoolwork.

2. EMOTIONAL SUPPORT Emotional support involves providing encouragement, but not direction, as the person points to communicate. For example, the facilitator may offer praise for a job well done, interest in what the person is typing to let him/her know someone is listening and encouragement to give the person confidence in him/herself.

“The facilitator needs to feel confidence and encourage me to succeed,” said Blair Brown. “I am often unsure and anxiety overtakes me. The strong support of a communication partner helps me to continue.”

Sue Rubin, college student, FC user and subject of CNN’s Emmy Award-winning documentary “Autism is a World,” explained that the FC user is not the only person that needs to be confident, but that the facilitator also plays an important role.

“Confidence makes independence happen,” she said. “I can now type independently with people I have just met because I am confident I can do it and they are confident it can happen because they see me typing independently with others. I gained confidence over time by being successful with each level of fading.”

3. COMMUNICATIVE SUPPORT Providing communicative support involves various forms of verbal prompts and cues to help the FC user stay focused in communication interaction, to provide feedback on the content of their message and to assist in clarifying messages. For example, the facilitator will read the message out loud to keep the FC user focused on completing his/her thought. Or, the facilitator may repeat a question to allow the person to refocus attention, if it seems to have drifted. Further, if the FC user is typing a message that seems unclear, the facilitator will read the message out loud and ask the FC user, “Is that what you meant to say?” or “Do you want to edit this?” This gives the FC user the chance to continue or to change the message as they wish.

Although Jamie is an experienced FC user, he said communicative support is very important, noting that “even though my typing is independent, I have to have a facilitator next to me to help me continue my message. I have a very difficult time staying focused so I ask for direction to keep me going.”

FC user Chandima Rajapakirana agrees, pointing out that “typing and the firm structure of a facilitator restrains the chaos in my brain and brings order to it.” The structure of feedback and attentional focus provided by an attentive and supportive communication partner helps the FC user to not only focus on the message he/she wishes to type, but to work on developing skills needed to become an independent typer.

“I can assure you that typing organizes my mind and body so I can function as a thinking person. People actually say low-functioning people with autism don’t need to learn academics because it is more important for us to learn functional skills,” said Sue Rubin. “They don’t understand that by typing and learning academics we are then able to think about what we want to do functionally, and with better body control, we have a better chance of being successful with that functional skill and the skills necessary for living in the community.” For Sue, learning to type helps her not only to organize her thoughts to communicate, but also to think about and organize her body to better engage in daily tasks.

Typed communication, with multiple forms of support provided by the facilitator, allows the FC user to communicate messages that differ in complexity and usefulness. This support, however, is highly individualized and based on specific needs; it does not look the same from person to person.

For example, one FC user may receive support at the hand with strong backward pressure after each keystroke; one may type with a light touch on the shoulder; another may type with one hand; yet another may work on developing a rhythm with two-handed typing.

This diversity of supports and styles of typing complicates any understanding of facilitated communication as a prescribed method. Instead, it is a dynamic and long-term process of identifying, implementing and evaluating communication supports, according to “Facilitated Communication Training Standards” (to read the standards, see selected readings on facilitate communication at www.breaking-the-barriers.org/addinfo ).
Breaking the Barriers

Facilitated communication is indeed controversial. A number of studies have failed to validate FC user authorship and have shown that a facilitator’s touch of the typist’s hand can influence the person’s pointing (Bebko, Perry & Bryson, 1996; Bomba, O’Donnell, Markowitz & Holmes, 1996; Cabay, 1994; Crews, Sanders, Hensley, Johnson, Bonaventura & Rhodes, 1995; Eberlin, McConnachie, Ibel & Volpe, 1993; Klewe, 1993; Montee, Miltenberger and Wittrock, 1995; Moore, Donovan, Hudson, Dykstra & Lawrence, 1993; Regal, Rooney and Wandas, 1994; Shane and Kearns, 1994; Smith and Belcher, 1993; Szempruch and Jonason, 1993; Wheeler, Jacobson, Paglieri & Schwartz, 1993).

On the other hand, other studies, using a range of testing situations and methods of documentation, have successfully demonstrated authorship on the part of the FC user (Broderick and Kasa-Hendrickson, 2001; Calculator and Singer, 1992; Cardinal, Hanson and Wakeham, 1996; Emerson, Grayson and Griffiths 2000; Janzen-Wilde, Duchan and Higgenbotham, 1995; Niemi and Karnan-Lin, 2002; Rubin et al, 2001; Sheehan and Matuozzi, 1996; Tuzzi, Cemin and Castagna, 2004; Weiss, Wagner and Bauman, 1996; Zanobini and Scopesi, 2001).

But according to Beukelman and Miranda, “In regard to a small group of people around the world who began communicating through FC [facilitated communication] and are now able to type either independently or with minimal, hand-on-shoulder support... there can be no doubt that, for them, [facilitated communication] ‘worked,’ in that it opened the door to communication for the first time... For them, the controversy has ended.” (p.327)

So despite the debate surrounding FC, many people with autism (and other communication-related disabilities) across the world continue to use facilitated communication. In fact, Tyler, alongside a committed group of FC users and allies through an advocacy group called Breaking the Barriers, is working to gain broader acceptance of the use of facilitated communication.

“Facilitated communication has been the foundation of all my included life experiences. Being able to communicate has allowed me to participate in regular education my whole life,” Tyler said. “I am currently in junior college taking algebra and a swimming class. FC has been so important in my life. We must advocate for others to get a voice.”

Breaking the Barriers is working to ensure that:

- people with disabilities who do not communicate meaningfully through speech have a means of communication
- that allows their fullest participation in the world
- people can communicate using their chosen method, and their communication is respected by others
- people with disabilities who use alternative forms of communication are active at the local, state and national levels in shaping public policy
- facilitated communication is accepted in practice and policy as an equal choice among augmentative alternative communication methods

Blair, in her college class last semester, summed up the importance of communication in her life: “I am slow to think I am accepted here, but it is getting better as students understand me. They must think my behavior is weird, but my typing gets them to think I am smart. When I type I can share with them how I feel and explain my weird behavior. Then we can be equal in class.”

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References


FACILITATED COMMUNICATION
One Family’s Success
BY NANCY BRADY

Our son, Nicholas, was diagnosed with autism when he was 3 years old. We learned about facilitated communication (FC) one year later. At the time, he was struggling with PECSs, and even simple matching tasks were difficult and unproductive. We needed a communication strategy that would help his body organize in a manageable way. Nicholas’ doctor always emphasized that he had an “output” problem, not an “input” problem, and suggested FC as a strategy for our little guy, who was struggling with motor planning issues.

After years of working with home support staff and therapists trained in FC, we knew that Nicholas could read, spell and type, but we did not know how to apply the strategy in school, where no one was willing to train and support him. Without access to typing at school, Nicholas was put in a position of not being able to ask questions, communicate what he knew or express himself in a complex manner. Even though we knew how smart he was, we still had to sit through Individualized Education Programs (IEPs) and hear all the things he could not do. Because of FC, we knew better, but our school district would not embrace the idea. It was more feasible for them to place our son in a segregated classroom for children with autism at a school across town.

That was not an option for us. Believing in Nicholas’ intellectual capabilities, and with a philosophy of inclusion as a basic tenant of family life, we felt that he had a right to learn grade-level academics and functional skills in a general education classroom, in his neighborhood school, along with his siblings and other friends who live on our street. We also believe that he has a fundamental right to communicate, and we are making tremendous progress in his quest to type independently, which is our goal. He is now able to express himself with complexity and deep thought using FC. And is he ever telling us a lot! He types, “listen to my typing because it is hard to tame my voice.” He also types, “Nick likes girl.”
changed our way of supporting him in his efforts to control his autism. We respect our son’s opinions and we honor his intellect. We talk to him as we do our other children. We do not talk about him, in front of him. We ask his input on all subjects, especially the ones that directly affect him. He has opinions of therapists that he works with and opinions of his teachers at school. He knows what foods he likes and why. He knows what rides he wants to go on at Disneyland and what rides are boring. He is a thinking, feeling, intellectual, nine-year-old boy with a lot to say. If only people would listen to his typing.

And that is the struggle that we are now facing. Few at his school will listen, much less support his right to communicate using FC. So our family is now on another trajectory—to find a different school, perhaps private, where the teachers will listen to Nick, presume his competence, treat him with respect and allow him to communicate and be educated with his peers in a typical, inclusive classroom, using FC.

Recently, we were together in a restaurant when Nicholas began flicking his fingers uncontrollably and squealing. I asked him how he felt. He typed, “I feel weird.” I then asked him what I could do to help him. He typed, “Stay still.” So I told him to stay still and he took a deep breath and relaxed for a few seconds, before his fingers start flicking once again. I appreciate the fact that he is coming up with his own remedies for controlling his autism.

Last week, Nicholas woke up one morning with severe anxiety and kept verbally repeating, “Nicholas is happy,” although his behavior demonstrated otherwise. He had tears in his eyes and was visibly upset about something. I got his Lightwriter and I asked him what I could do to make him feel better. He typed, “Talk about Dad.” So, we talked about Daddy, who was away for the weekend skiing. I asked Nicholas if he knew where Daddy was, and he typed, “Fly on the airplane.” Yes! We talked about Daddy coming home that night and we called Daddy’s cell phone and left him a message. After typing and discussing it, his anxiety disappeared and he was able to relax. Nicholas was not able to communicate these thoughts to me verbally, but through his typing, I was able to understand what was wrong and help him feel better.

Thankfully, FC has provided Nicholas with a way to communicate. We have found a strategy that allows dialogue and conversation in our family life, and a way for Nicholas to show those at school how smart he is. Nicholas is learning to read aloud the words that he has typed, and his spontaneous, expressive language is increasing daily. We have a happy, confident, well-adjusted son who is smart, funny and willing to learn. He now has the ability to express himself through FC, if his voice is unwilling or unable. All we have to do is listen.