

# The Maturing of Facilitated Communication: A Means Toward Independent Communication

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## Abstract

Facilitated communication (FC) can be a successful means for people to learn to communicate effectively and independently. The preponderance of peer-reviewed articles supports FC as a useful tool for developing communication skills. While there has been a chasm of difference in qualitative versus quantitative studies on FC, researchers have produced a body of current literature confirming the method. Many people with significant intellectual disabilities, through the use of FC, have been able to demonstrate their ability to successfully communicate. We, as a profession, now need to respond with collaborative scholarship. In addition, revised position statements must be developed reflecting the past research findings and encouraging future research.

## Keywords

facilitated communication, multivariate analysis, severe disabilities, facilitated communication

Facilitated communication (FC) has been used and formally studied in the United States since its introduction in 1990 and continues until today. Popular media has served as a form of public jury for the method, vacillating from framing it as a great discovery to proclaiming it a myth. The method has appeared on TV shows and has been the topic of several high profile documentaries, both substantiating FC and calling it into question. Professional research has been seriously split down the lines of quantitative and qualitative methods of inquiry, where the former has been frequently, but not always, unable to verify significant gains by users of the method or reported serious concerns about the authenticity of the produced communication. The latter, qualitative research, consistently reports authentic communication by users of FC, often from the users of the method themselves, and served as a means to develop the infant FC method through a maturation process. The authors will outline the maturation process of FC and provide specific examples that have evolved over time. The authors conclude that there is ample credible evidence that FC can be used effectively and opine that professional organizations should create positions that call for the proper use of FC and appeal to the field to review previous scholarship that outlines best practices for the safe and effective use of FC and, where needed, engage in a systematic process of research to enhance such best practices.

## Research on FC

In 1990, a pivotal article “Communication Unbound: Autism and Praxis” by Dr. Douglas Biklen was published in the *Harvard Educational Review*. In this article, Biklen described FC, a method that he has

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observed his Australian colleague Rosemary Crossley use to encourage people who had no or limited reliable communication proficiency to speak. FC is a process to initially encourage communication, in the form of prompts, supports, or stabilizing of the hand or arm, which would then, as soon as possible, be faded. In referring to the use of FC, Crossley (1994) stated, "The ultimate goal is for students to be able to use the communication aids of their choice independently" (p. 3).

FC, or supported typing, is a form of augmentative or alternative communication (AAC), in which people with communication challenges or limitations point to or type their messages. FC involves both a person who needs support or facilitation to communicate and a communication partner. The communication partner provides support in a variety of ways. The communication partner might provide emotional support to encourage communication or might help the person to focus on the keyboard, array of pictures, letters, or words throughout the communicative interaction. Communication partners also might provide physical support to stabilize the person's movement, inhibit impulsive typing, or to encourage the initiation of typing or pointing. When providing physical support, the facilitator should never lead the person to type or point.

Within several years of Biklen's (1990) article on FC as a potential method for increasing communication in people who had not yet developed effective and reliable communication skills, numerous published studies challenged the authenticity and authorship of the communication produced through facilitated or supported typing (Bebko, Perry, & Bryson, 1996; Eberlin, McConnachie, Ibel, & Volpe, 1993; Wheeler, Jacobson, Paglieri, & Schwartz, 1993). These studies were instrumental in seriously slowing the acceptance of FC for increasing communication skills in such individuals. Despite the challenges to the method, many practitioners, parents, and individuals who experienced communication challenges persisted in using and refining the FC method to ensure the authenticity of authorship of the typed message.

During this same time period, early and mid-1990s, qualitative researchers continued to investigate FC as a means to improve its strategy, mitigate facilitator influence, and allow individuals with disabilities to tell their own stories (Bernardi, & Tuzzi, 2011; Biklen & Cardinal, 1997; Biklen & Duchan, 1994; Biklen, Saha, & Kliever, 1995; Broderick & Kasa-Hendrickson, 2001; Crossley, 1997; Emerson, Grayson, & Griffiths, 2001; Goddard & Goddard, 2012; Grayson, Emerson, Howard-Jones, & O'Neil, 2012; Janzen-Wilde, Duchan, & Higginbotham, 1995; Niemi & Karna-Lin, 2002; Robledo & Donnellan, 2008; Weiss, Wagner, & Bauman, 1996). Since the inception of FC, well over 100 qualitative articles have been published in professional peer-reviewed journals, as compared with around 40 for quantitative studies. Furthermore, since the late 1990s, the prevalence of naturalistic peer-reviewed journal articles has dramatically increased, while only a handful of quantitative studies have appeared in peer-reviewed journals after 1996 (Cardinal & Robledo, 2012). This may demonstrate that researchers have come to recognize that they learn much more about the process of FC through qualitative, as compared with quantitative research. Where nearly all quantitative research has been focused on the efficacy of FC, research using qualitative methods of inquiry have focused more on the systematic development of the method, searching for what works best, for whom and the conditions thereof.

The qualitative studies on FC chronicle the life stories of those using FC and will serve as a historical record for many years to come. In fact, one could contend that these studies can be used as an evolutionary roadmap showing the migration of levels of support, fading of that support, while minimizing the threat of facilitator influence on the speaker. Clearly, many of those who were judged by the past quantitative research as not typing their own words and thoughts were often doing so, as evidenced by eventually typing their own thoughts independently of physical support from others. In referring to those like Sue Rubin who are typing independently, Mirenda and Beukleman (1998) stated, "For them, the controversy has ended" (p. 327).

While the strongest evidence of the efficacy of FC comes from qualitative research, other methodologies have provided support for FC. Below is a short list of studies using quantitative methods that have provided evidence for the efficacy of FC, while also serving to test the individual methodological components of FC.

- Video eye-tracking of the FC user's eye gaze to verify that the individual letters, or series of letters, were targeted by the individual before ever making the first move of the hand toward a target (Grayson et al., 2012).

- Linguistic analysis of typed messages that reveal the communicators' unique use of language (Niemi & Karna-Lin, 2002; Tuzzi, 2009; Zanobini & Scopese, 2001).
- Evidence of speech before and during typing (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick, & Hanson, 2009).
- Message passing studies in which many individuals demonstrated authorship, where the study's methods were designed to desensitize participants to anxiety over the course of the study (Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuozzi, 1996; Weiss et al., 1996).

## FC and the Popular Media

The impact of the popular media on FC is unavoidable. It seriously affects how schools, agencies, and families perceive the method. Complicating the impact of the popular perception of FC in the media over the past 24 years is the notion that there is no single conclusion. The treatment of FC in the media stems equally from high support to portrayal as a hoax. An example of this contrast is the in-depth journey of several users of FC, chronicled by two highly acclaimed documentaries by Academy Award winning director Gerardine Wurzburg, in contrast to the scathing attack in 2005 *Washington Post* article by Lisa Barrett Mann on a person who learned to communicate through FC and later verified her communication through the extensive and independent typing of her own words (Rubin et al., 2001). In the article, titled "Oscar Nominee: Documentary or Fiction?" Mann challenged the authenticity of the then 26-year-old Sue Rubin's communication in the Oscar nominated CNN documentary film, *Autism Is a World* (Bedingfield, Biklen, & Wurzburg, 2004). Sue Rubin, who was diagnosed with autism with an IQ range in the low 30s twenty years previously, was now able to type independent of physical touch. Rubin emphatically credits FC with her ability to communicate her thoughts through typing. Her most recent IQ testing added 100 points to the assessment of her intelligence. In addition, she graduated from high school with a diploma and from college with a degree in history. Yet Mann felt compelled to question Rubin's ability. At this point, one might ask what someone with an uncooperative body needs to do to prove their intelligence, and perhaps even their humanness. Sue Rubin has not been the only individual to have her intelligence challenged (and insulted) and Lisa Barrett Mann is not the only one to succumb to this stereotype. Peyton Goddard is another example of an individual who was diagnosed at 6 years old as "severely mentally retarded" until she was introduced to FC and had a reliable and effective means of communicating through typing. Sixteen years later, when Peyton finally gained a dependable mode of communication through the process of FC, she was recognized as an intelligent woman. She eventually shattered her previous prognosis when she graduated from college and gave the valedictorian speech at her college graduation. She and her mother co-authored a book titled *I am Intelligent* that chronicled Peyton's journey throughout her life (Goddard & Goddard, 2012). In 2010, the documentary film, *Wretches & Jabberers and Stories From the Road*, was released featuring several individuals with autism from around the world who typed to communicate and were previously thought to be cognitively delayed and communicatively challenged. The examples are many of the individuals who used FC to learn to communicate their thinking in writing, yet who serve as victims of those who refuse to acknowledge their thoughts as their own. The frustration and pain of this would seem insurmountable, yet they persist as champions of their own intelligence while crediting the process that helped them discover a way to communicate it to others, and maybe even themselves through FC.

## The Maturing of FC

Qualitative and quantitative research and practice in FC over the most recent 15 years has resulted in important improvements in the effective implementation of FC. The systematic examination of the various components of facilitation by the large number of qualitative research articles mentioned above has served to shepherd the development of the practice of FC. In addition, these qualitative studies often take place in the natural environment where FC is being used and the researchers talk with the users of FC and are informed by their intimate understanding of the method. Changes in the use of FC appear within the various components of FC such as patterns of fading support; proximity of the FC user to the facilitator; degree, location,

and type of resistance applied; and the relationship that exists between the communication pair. In terms of patterns of fading support, for example, practitioners began fading the support much sooner than they had in the early years of FC, which resulted in mitigating the issue of authenticity and authorship—this evolving process has led to the more sophisticated method of FC we know today. There is greater urgency to fade support so that an individual is typing as independently as possible. Once individuals began to type independently, that is, no one is touching the typer or providing a simple pincer grasp on the typist's shirt, after learning to type via FC, there is no longer a concern about who is doing the typing.

Another example of the maturing of FC has been the increased use of multiple facilitators to the degree that it has become common practice. Using multiple facilitators greatly reduces the chance that a facilitator can purposefully or unintentionally transfer his or her own thoughts onto the typed output. Using multiple facilitators also provides the opportunity for the speaker to substantiate his or her writing with others or for a school or agency to provide greater assurance that the words typed are actually from the FC speaker. The topic of the evolution of FC over the past 15 years chronicling the maturing of the method is a worthy topic for stand-alone manuscript.

For clarity, it is important to note that not everyone who uses facilitation will or has become independent 100% of the time. Many use the method to learn to point to words, symbols, or keys on a keyboard toward a goal of greater independent communication skills over time. That many individuals have become independent typists and credit facilitation and its fading of it for their developed abilities demonstrates that the method can result in authentic, original communication and authorship.

## **Professional Position Statements on FC**

There are now far more studies that support FC than refute it. More convincingly, nearly all of the studies unable to capture the effectiveness of the method or concluding facilitator influence occurred more than 15 years ago. Since that time, nearly all peer-reviewed studies on FC have been supportive of the method, and these studies have served to help the method of FC mature into the more robust method we have today. The method of FC has evolved to a point where its authenticity of authorship has been enhanced, albeit through trial and error. It is now time to develop professional position statements that reflect these newer studies. A group of brave individuals has demonstrated effectively the original contentions of FC that it can work for some people, under some circumstances (such as Rosemary Crossley and Douglas Biklen conjectured from the start). Further research is needed to better understand whom FC most benefits and the most effective ways to detect, reduce, or eliminate any potential facilitator influence. A renewed examination of FC and revised position statements should encourage more research to determine who is more likely to benefit, when, and under what conditions. These position statements should systematically map the best practices to use FC. These recommendations appear to be warranted at this time.

## **Conclusion**

FC is effective, at least for some people under specific circumstances. This seems unequivocal as evidenced by the vast number of peer-reviewed journal articles supporting the method. This article identifies specific quantitative research showing clear evidence of the efficacy of FC as judged by unbiased peer reviewers around the world. There are more quantitative studies unable to substantiate FC, or that identify the threat of facilitator influence, but these studies are 15 to 20 years old, and as outlined within, FC has significantly evolved during this time period. Over the past 15 years, there have been as many quantitative studies finding value in FC, and all of these studies pale in comparison with more than 100 peer-reviewed naturalistic studies that authenticate the method. After all, these studies focus on the lived experiences of those individuals who use the method to communicate. Logically, when the preponderance of peer-reviewed articles overwhelmingly support FC, and that these results are socially validated by the very people they were designed for, one must accept that premise or produce a current and equal set of published peer-reviewed articles and real-life examples that conclude the opposite—and such evidence does not exist.

People who were officially diagnosed with significant intellectual disabilities began to use the method and now can communicate through typing without anyone touching them. And each identifies FC as the

method that brought him or her to this point. That alone should suffice; however, clear scientific studies provide evidence of the efficacy of FC. Then to remove all doubt, add more than 100 peer-reviewed published studies, where each thoroughly examines the questions surrounding FC and point to its authentic nature. The contra argument holds tightly to roughly 35 studies that are approximately 15 to 20 years old, 90% of which occurred prior to the greatest development in FC since its inception, independent typing.

FC researchers have done what we have asked of them, what is implied in our profession. They have produced a body of current literature confirming the method according to accepted research methodology as verified by the “gold standard,” peer review. Many of the people we serve, those with severe disabilities, have proven in every way they can that they are smart and that they have done so using FC. We as a profession now need to respond with fairness and develop position statements that encourage new scholarship and embrace and enhance the best practices of FC. Both qualitative and quantitative researchers should now make efforts to collaborate with each other to provide the necessary research base to support the use of FC that will satisfy the profession and provide those who may benefit from FC the needed support from schools and agencies.

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