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Assessing the Validity of Facilitated Communication for Individuals with Autism and/or Moderate to Severe Disabilities

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These starred papers submitted by Diane M. Nichols in partial fulfillment of the requirements for the Degree of Master of Science at St. Cloud State University are hereby approved by the final evaluation committee.

TO SEVERE DISABILITIES

INCLUSION AND THE SUPPORT OF STUDENTS THROUGH
PROGRAM MODIFICATION

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B.S., Mankato State University, 1976

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in Partial Fulfillment of the Requirements

for the Degree

Master of Science

St. Cloud, Minnesota

November, 1984

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School of Graduate and Continuing Studies

**ASSESSING THE VALIDITY OF FACILITATED COMMUNICATION
FOR INDIVIDUALS WITH AUTISM AND/OR MODERATE
TO SEVERE DISABILITIES**

**INCLUSION AND THE SUPPORT OF STUDENTS THROUGH
PROGRAM MODIFICATION**

by

Diane M. Nichols

B.S., Mankato State University, 1976

Starred Papers

Submitted to the Graduate Faculty

of

St. Cloud State University

in Partial Fulfillment of the Requirements

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St. Cloud, Minnesota

November, 1994

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Berlin schoolteacher, Wilhelm von Osten (1904) produced convincing evidence that animals (specifically horses) were able to think, talk, and even calculate if instructed correctly. The approach implemented by Herr von Osten consisted of assigning a number to each letter of the alphabet. The horse was then expected to learn the number/letter association and demonstrate an understanding of the association by tapping his hoof on a board mounted in front of him. B.S., Mankato State University, 1976, was thought to be able to combine letters to form words and words to form sentences, thereby expressing his thoughts (Hediger, 1981). Herr von Osten's theory was eventually challenged and it was ultimately determined that the horse was merely responding to subtle trainer cues (Sullivan, 1992).

A similar controversy currently surrounds the use of facilitated communication as a means of accessing the communication skills of individuals with moderate to severe mental impairment (MSMI), and individuals with multiple disabilities suppress their ability to communicate. Submitted to the Graduate Faculty of St. Cloud State University in Partial Fulfillment of the Requirements for the Degree of Master of Science. facilitated communication is viewed as a breakthrough for the Degree Master of Science able to reveal well developed language skills for hundreds of individuals who possess severe language deficits (Greco, 1992). For others, it seems a visionary phenomena designed to fulfill the dreams of parents who imagine conversing with their nonverbal child for the first time (Calculator, 1992).

St. Cloud, Minnesota

November, 1994

Chapter I

INTRODUCTION

Berlin schoolteacher, Wilhelm von Osten (1904) produced convincing evidence that animals (specifically horses) were able to think, talk, and even calculate if instructed correctly. The approach implemented by Herr von Osten consisted of assigning a number to each letter of the alphabet. The horse was then expected to learn the number/letter association and demonstrate an understanding of that association by tapping his hoof on a board mounted in front of him. The horse, named Clever Hans, was thought to be able to combine letters to form words and words to form sentences, thereby expressing his thoughts (Hediger, 1981). Herr von Osten's theory was eventually challenged and it was ultimately determined that the horse was merely responding to subtle trainer cues (Silliman, 1992).

A similar controversy currently surrounds the use of facilitated communication as a means of accessing the complex thought processes of individuals. Often that population includes those individuals who are moderately to severely mentally impaired (MSMI), and individuals with autism, whose disability or multiple disabilities suppress their ability to communicate their thoughts and desires. For some, facilitated communication is viewed as a breakthrough technique able to reveal well developed language skills for hundreds of individuals assumed to possess severe language deficits (Green, 1992). For others, it seems a visionary phenomena designed to fulfill the dreams of parents who imagine conversing with their nonverbal child for the first time (Calculator, 1992).

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Facilitated communication has not been well defined operationally and research is just beginning to surface with regard to the effectiveness of its several components.

Simply stated, facilitated communication is a method whereby someone (the facilitator) provides emotional and mostly physical support to an individual with physical and

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scenario might witness the facilitator sitting to one side of the client while providing light support to the client's arm or head. The purpose of the facilitator is not to guide the communicator's finger to the letters, rather the opposite is true. The communicator is presumed to be in charge of the direction of the pointing as the facilitator offers limb stability to the client.

The degree of facilitation required varies greatly among individuals. Crossley and Remington-Gurney (1992) suggested a continuum in the provision of physical guidance ranging from hand holding (actually shaping the client's hand to isolate a pointing finger), to a light touch on the wrist, elbow, shoulder, or sleeve of the client. At the least intrusive end of the continuum is independent typing by the client with no physical contact from the facilitator. This physical guidance allows the client to access the illustrated letters of the alphabet and ultimately spell out their thoughts.

The only other tool necessary for facilitation is some type of alphabet presentation. The manner in which the alphabet is presented varies. An alphabet or language board consisting of the alphabet illustrated on paper in a pictorial representation of a keyboard is one variation. The Canon Communicator, a typewriter-like device is another. A typewriter or computer can also be used. Augmentative devices specifically designed to assist persons with disabilities are alternative choices, as well (Hudson, Melita, & Arnold, 1993).

Facilitated communication has not been well defined operationally and research is just beginning to surface with regard to the effectiveness of its several components.

Simply stated, facilitated communication is a method whereby someone (the facilitator) provides emotional and mostly physical support to an individual with physical and communicative impairments for the purpose of assisting them with spelling words on a keyboard or other letter display in order to convey thought (Green, 1992). A common scenario might witness the facilitator sitting to one side of the client while providing light support to the client's arm or hand. The purpose of the facilitator is not to guide the communicator's finger to the letters, rather the opposite is true. The communicator is presumed to be in charge of the direction of the pointing as the facilitator offers limb stability to the client.

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The facilitated communication training strategy (FCT) was developed at the DEAL Communication Center (Dignity through Education and Language) in Australia operated by Australian teacher, Rosemary Crossley. The emergence of FCT can be directly attributed to Crossley. Its purpose was to teach hand skills necessary to access augmentative communication devices effectively. In particular, facilitated communication was designed for individuals with severe communication impairment (SCI) compounded by impaired hand function (Crossley & Remington-Gurney, 1992).

Crossley (1992) described FCT as a strategy used with individuals with SCI who are unable to access a communication aid, but for whom direct access with their hands is a realistic and desirable goal. Candidates for such a program include individuals whose neuromotor impairments inhibit hand usage for signing and/or writing and significantly affect their use of augmentative devices.

FCT was designed to assist individuals possessing relatively minor neuromotor impairment. The initial purpose of FCT was to provide a means of making choices and allow some level of communication while developing the manual skills necessary for augmentative equipment. As hand usage skills increased, facilitation would decrease. Independent access of a communication aid was the ultimate goal for these individuals (Crossley, 1992).

Crossley's intent and usage of facilitated communication largely served a population of individuals with cerebral palsy possessing average intellectual ability. Douglas Biklen, Division of Special Education and Rehabilitation, Syracuse University, Syracuse, New York, transported facilitated communication to the United States and is responsible for popularizing its use with individuals possessing other, more severe disabilities, most notably individuals with autism (Green, 1992).

Autism is a rare brain disorder affecting social, cognitive, behavior, and language development. Autism is characterized by highly disordered communication skills

including muteness and echolalia, unusual responses to external stimuli, difficulty with socialization and relationships, and an inclination toward stereotypical behavior (Biklen, Morton, Gold, Berrigan, & Swaminathan, 1992). Autism is present very early in life and symptoms are not considered to be susceptible to sudden transformation (Rimland, 1991). Another critical characteristic to consider concerning autism as described by Rimland (1993b) is that most individuals with autism have unimpaired finger dexterity and, in fact, are usually described as being especially dexterous and coordinated.

Autism is presumed to be the result of a neurological disorder affecting cognitive as well as motor and emotional functioning (Biklen et al., 1992). Biklen (1992a) suggested that facilitated communication actually assists these individuals in overcoming neuromotor difficulties and helps with the lack of self-confidence seemingly common to individuals with autism.

FCT usage has dramatically increased over the past several years (Prior & Cummins, 1992). Along with the increased interest and usage of facilitated communication has come disagreement concerning research techniques used to validate FCT and, ultimately, a line has been drawn separating supporters from opponents (Wheeler, Jacobson, Paglieri, & Schwartz, 1993). Support is typically represented by single case studies and/or personal experiences documented by the facilitator(s) which are regarded as adequate proof of validity. Proponents of FCT are armed with numerous sources of support of successful facilitated communications (Calculator & Singer, 1993).

On the other hand, opponents of facilitated communication will argue that participants are merely responding to subtle and sometimes overt cues provided by the facilitator, and ultimately communicating the thoughts and desires of the facilitator. This suggested presence of facilitator influence, the Clever Hans phenomenon, is beginning to find sanction in an emergence of current research refuting the validity of facilitated communication.

The purpose of this paper was to examine the controversy surrounding the use of facilitated communication with individuals who are moderately to severely impaired and/or individuals with autism. Specifically, this paper analyzes professional literature and research supporting facilitated communication as well as arguments opposing it in an effort to either substantiate facilitated communication or determine it invalid.

Since its reception, facilitated communication has been the focus of controversy. This controversy has stirred a diverse spectrum of emotions, among them hope, skepticism, confusion, and even resentment. These mixed reactions to the concept are justified, for suddenly individuals thought for years to be minimally communicative at best are seemingly producing complex and sophisticated writings (Donnellan, Sabia, & Majure, 1992). Central to the controversy is the debate involving the physical touch component of facilitated communication. The physical touch element is possibly the most significant independent variable in facilitated communication (Donnellan, Sabia, & Majure, 1992).

Physical support and prompting together with the use of various augmentative equipment have long been considered a necessary component of many facets of skills training offered to individuals with autism and/or MSMI (Crossley, 1990; Green, 1992). Crossley (1990) maintained that facilitator assistance differs from the physical assistance typically provided during skills training activities (i.e., classroom activities) in that the facilitator should not overpower the communicator. Prior and Cummins (1992) explained that the facilitator's role is to make physical contact solely to overcome or minimize psycho emotional and/or neurophysiological problems related to achieving success. These authors further clarified this concept by explaining that the facilitated communication technique differs from graduated guidance as offered in typical learning situations, in that the intention of other movements is the responsibility of the message

Chapter II

REVIEW OF LITERATURE

Since its inception, facilitated communication has been the focus of controversy. This controversy has stirred a diverse spectrum of emotions, among them hope, skepticism, confusion, and even resentment. These mixed reactions to the concept are justified, for suddenly individuals thought for years to be minimally communicative at best are seemingly producing complex and sophisticated writings (Donnellan, Sabin, & Majure, 1992). Central to the controversy is the debate involving the physical touch component of facilitated communication. The physical touch element is possibly the most significant independent variable in facilitated communication (Donnellan, ^{et al.} Sabin, & Majure, 1992).

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sender rather than the individual offering guidance. Biklen (1992a) stressed that the role of the facilitator is not to assist the communicator in making letter selection; rather, it is to isolate the index finger or stabilize the arm or wrist and gently pull back the communicator's arm following each selection.

Also essential to the success of facilitated communication is the relationship between the communicator and the facilitator. Biklen (1992b) emphasized that the supportive relationship between teacher and student has been discussed and studied in education for decades. Biklen suggested that physical contact between the communicator and facilitator may be irrelevant, citing the unique bond established between facilitator and communicator is of utmost importance. This relationship has thus far been described in a mystical or spiritual sense, attributing communicative success to the facilitator's belief in the intellect and ability of the individual with the disability (Calculator, 1992; McLean, 1992). Often, if expectations are high, individuals will respond favorably and meet those expectations. On the other hand, individuals from whom little is expected, specifically whose communication needs are consistently preempted by others, will often display indifference (Calculator, 1985, 1988; MacDonald, 1985; Mittler & Berry, 1977). There is little incentive for a person to communicate independently if all needs are met with little or no effort on their part. Calculator (1992) implied previously dormant competencies may surface when expectations are raised and opportunities to functionally use skills are increased.

Biklen (1992a) addressed this phenomenon when describing various components describing the facilitator's role. One facet of the facilitator's role is to avoid testing for competency. Biklen maintained it is important to let the communicator know that you deem them competent while realizing that the communicator's thinking and literacy abilities will reveal themselves over time. An additional component describing the role of the facilitator is that of generalizing. Generalizing became apparent to Biklen when

observing that communicators often develop a high level of communicative ability with one or two facilitators and will require encouragement and repeated attempts to generalize when other facilitators are introduced. A possible explanation offered supporting this inability to generalize implies a basic distrust of some facilitators and suggests that perhaps the communicator chooses not to share their most private thoughts solely to appease the desires of those who feel the need to prove their existence (Donnellan et al., 1992).

Other aspects of facilitator role as described by Haskew and Donnellan (1992) implied a more psychic or philosophical base. These authors stressed the importance for all to attain a clear sense of identity. It is their suggestion that the birth of facilitated communication has provided the opportunity for individuals with SCI to travel the path to self-identity and personal growth not available to them before.

Recently, some supporters have reported that their clients possess an uncanny awareness of their facilitator's thoughts. Supporters suggest the presence of a sixth sense as an explanation of this telepathic ability. This sixth sense allows the communicator to understand what others think and feel, thereby allowing them to transmit their thoughts to other non-verbal acquaintances or facilitators (Haskew & Donnellan, 1992).

Facilitated communication lies within an emotionally and spiritually charged atmosphere. While parents and care-givers understandably view facilitated communication as an opportunity to penetrate the silent world of the individual in their care and begin dialogue with that individual (Calculator, 1992), researchers express concern over creating a world of misguided, false hope for these care-givers.

Green (1992) cited several issues which possess ample potential for harm without proper validation. Besides the obvious potential for raising false hopes, the author identified ethical issues such as inflicting parental guilt, which might cause the parent or care-giver to question how they could ever have treated this individual as retarded.

Substantial risk exists for the thoughts and desires of others to be imposed on vulnerable individuals, knowingly or not. The implications of using facilitated communication to complete IQ testing or college entrance exams or the use of facilitated communication to make life-changing decisions such as guardianship are great causes for concern and should be given serious consideration. Suddenly, a population traditionally requiring outside advocates, seems capable of self-advocacy. However, without proper validation that the thoughts expressed via facilitated communication are indeed those of the client, action taken based solely on messages received via facilitation could in fact be a gross violation of the individual's most basic rights. On the other hand, denying the opportunity to communicate choices to an individual who might, in fact, be capable of doing so, also suggests a violation of basic rights (Green, 1992).

Donnellan et al. (1992) stated that the danger of raising false hopes is far less significant than the danger implied by failing to offer facilitated communication as an option. These authors suggested that families have endured and survived far greater disappointments than what they might experience should facilitated communication fail. Green (1992) cautioned acceptance without validation, implying the potential for great harm to various individuals, both emotionally and ethically. Messages revealed via facilitation are often thematic. Common themes reported from facilitated communications around the world include expressions of frustration over being handicapped, wishing to be normal, loneliness, desire to attend regular schools, the thrill of being able to spell through facilitation, feeling trapped, sexuality, episodes of abuse, and poetry. Histories of abuse, in particular sexual abuse, became an early common issue in facilitated communication (Green, 1992; Haskew & Donnellan, 1992).

Rimland (1992) cited specific instances in which facilitated communication was used to accuse parents and teachers of sexual or other abuses. A California teacher was facing 90 years in prison if allegations that he molested four teenage boys in his class

were judged true. A Washington family exhausted college and retirement funds challenging abuse allegations against their autistic daughter. A New York family incurred \$50,000 in legal expenses fighting abuse charges (successfully). Although not currently allowed as admissible evidence in court (Haskew & Donnellan, 1992), allegations made through facilitation have managed to create some very uncomfortable situations, resulting in significant emotional pain for the parties involved. In 1992, at least 50 legal cases in the United States alone existed involving allegations of sexual abuse. In all cases, the information was obtained through facilitated communication. Several similar cases have already occurred in Australia and some have surfaced in Europe as well (Green, 1992). The possible impact these cases could have on individuals and families is staggering. Parents, teachers, and care-givers face extensive prison sentences and financial depletion fighting charges that are accessed through facilitated communication.

One such case presented before the U.S. District court, Northern District of New York, January, 1994, involves a 17 year old girl, Jenny, who is autistic and mentally retarded. Jenny's parents have brought suit on her behalf. Named as defendants are the county, the County Commissioner and Deputy Commissioner, the Department of Social Service, the County Attorney and caseworker, Syracuse University, Douglas Biklen, and the girl's teachers and teacher's aide.

Jenny does not speak or write and has very limited functional skills. Jenny lived at home. The lawsuit stems from allegations made by the teacher's aide, who also provided respite care for Jenny. In April, 1992, this woman reported to the school that Jenny had accused her father of raping and sodomizing her. Jenny also reportedly stated that her mother was fully aware of these occurrences. This information was conveyed through facilitated communication with the aide holding Jenny's hand over an alphabet board while Jenny pointed to the letters and allegedly transmitted this message. In fact,

Jenny actually facilitated a message accusing not only her father, but the teacher's aide, an uncle, and a relative named Poppy. The allegations toward anyone other than Jenny's father, however, were disregarded.

In November, 1991, Jenny was forced to undergo extensive medical examinations for the purpose of obtaining medical evidence of sexual abuse. The medical examinations revealed the contrary, suggesting there had been no sexual abuse of Jenny. Nonetheless, the county continued its investigation and prosecution of the case. Jenny was removed from her parents' home and contact with her parents was limited to supervised visits. This interruption in family contact continued until September, 1992.

Following six days of hearing in September, 1992, the court ruled the testimony to be hearsay. The petition was withdrawn. In November, 1992, the Family Court of New York dismissed the petitions for abuse and neglect. Unfortunately, a great deal of harm had already been imposed. Jenny's parents, both in the field of education, had suffered a great deal of mental and emotional pain, including temporary loss of custody, public humiliation, and depression. Their lawsuit citing unlawful investigation and malicious prosecution regarding alleged abuse and neglect of their daughter, requests a judgment of \$10,000,000, plus punitive damages for loss of custody, loss of income, pain, suffering, psychological injuries, mental anguish, and depression (Zwiebel, Brody, & Gold, 1994).

This and other legal cases as described earlier, hinge on the issue of research to validate facilitated communication as a reliable means of communications for individuals with severe disabilities and/or autism. Many opponents of facilitated communication cite a lack of empirical data to support its effectiveness (Rimland, 1991; Wheeler, Jacobson, Paglieri, & Schwartz, 1993).

Empirical validity testing requires a formal, documented, scientific approach to objectively gather and interpret data. Biklen (1992b) challenged the very definition of

empirical research proposing that qualitative research and quantitative (empirical) research both rely on systematic experimentation and observation. A major difference, however, lies in the fact that empirical validity testing utilizes strict experimental design control procedures which systematically test for internal and external validity factors in an effort to reduce possible contamination of the experiment (Gay, 1992).

Behavioral disciplines often experience a lag between the clinical application of a new treatment and the formal empirical validation of that treatment. New treatments are most often anxiously embraced in situations where prior treatments or procedures have not been particularly successful and where the problem itself is still not fully understood (McLean, 1992). Beukelman (1993) agreed, stating interventions are often expedited to become routine procedures before efficacy studies are completed. This is particularly true of domains displaying a pressing need. Facilitated communication, existing in such an emotionally charged atmosphere is an example of such eagerness to adopt a technique without validation, rendering it void of objective evaluation (McLean, 1992). Donnellan (1984) recommended that in the absence of conclusive data, educational, as well as other decisions, should be made based on an assumption that will produce the least negative effect if proven false or incorrect.

Proponents of facilitated communication maintain that the communicative exchange is actually damaged or destroyed by the negative feelings generated by empirical testing. They argue that competency testing actually undermines the confidence of the individual to be tested and subjects them to unnecessary pressure. Their recommendation is that validation should be based on natural occurring circumstantial evidence (Green, 1992).

In the absence of empirical data, investigators (Biklen et al., 1992; Crossley & Remington-Gurney, 1992) rely on qualitative findings to substantiate that messages revealed through facilitated communication are that of the client and not the facilitator.

Calculator & Singer (1993) cited several sources of support for individual not facilitator transmittal, including client uniqueness in typographical errors (e.g., striking two keys simultaneously or repeatedly striking the same key) and invented spelling evident with different facilitators. Other factors cited as support for the absence of facilitator influences include the use of unusual phrases and sentences (e.g., swearing), divulging information unknown to the facilitator, content which reveals aspects of the individual's personality, and the fact that the amount of physical contact provided by the facilitator decreases with time.

Qualitative studies rely heavily on methods adapted from anthropology and sociology. Components of qualitative research include observation, videotaping, narrative recording, analysis of narrative data through discussion, interviews, and the use of informants (Green, 1992).

Qualitative research is often based on single case studies and is anecdotal in nature. Numerous case studies involving successful facilitated communications have been reported. All are similar in design. Typically, a candidate for facilitated communication is identified and facilitated communication is implemented. FCT does not necessarily require a great deal of facilitator training. In some instances, as experienced by this author, a quick how-to explanation is deemed adequate to begin facilitation. In other cases, however, facilitators undergo many hours of training.

Biklen (1992a) described three case studies which possess similarities to most reported accounts of successful facilitation. Neil, 25 years old, does not speak. Communications for Neil are typically screaming, moaning, rocking, and pounding objects on a desk. Autism is the label given him. The majority of his school career was spent in special education classrooms for students with severe retardation. Facilitated communication has enabled Neil to speak mostly with two or three word responses indicating an awareness of his environment and understanding of abstract concepts. An

example of Neil's communication when asked to complete the sentence "When people see me they think I probably _____," Neil typed with hand support, "am mean."

Mark, age 7, also labeled autistic, does not speak, is prone to self-injurious behavior (SIB), and displays aggressive behavior toward others. He does not make eye contact, frequently laughs loudly, and claps his hands in front of his face. One year following his introduction to facilitated communication, Mark, as a first grader, was producing communications displaying rather abstract thinking. An example of one of his communications achieved through hand supported facilitated communication is as follows:

"I AI DONT WANT TO BE AUTISTIC
NOBODY REALLY ZUNDERSTANDS WHAT I FEEL LIKE
IT IS VERY LONELY ANDI OFTEN FEEL LOUSY
MY MOOD IS BAD A LOT I FEEL LESS LONELI
WHEN I AM WITH KIDS"

The third student, Maggie, age 14, can speak but her speech is echolalic and preserverative in nature. Maggie reportedly wrote Biklen a letter in which she remarked that facilitated communication "HAS MADE MARVELOUS CHANGES IN MY LIFE ANT THAT OF MMANY INDIVIDUALS WHO ARE STRANGERS IN THIS WORLD." Biklen (1992a) reported that Maggie's facilitation demonstrates a commonalty of messages conveyed by individuals with similar communicative disorders, in that their typing is far more sophisticated than their spoken word.

CBS News 60 Minutes aired an episode entitled *Less than a Miracle* on February 20, 1994. This story featured Arthur, a 17 year old individual diagnosed autistic and severely retarded who reportedly has raised his IQ to 106 with facilitated communication. With Arthur's mother facilitating, Morley Safer, 60 Minutes interviewer, asked Arthur if there had been an historical handshake agreement signed the day before.

Arthur responded Y-E-S. When asked between whom, Arthur responded A-R-A-F-A-T A-N-D R-A-B-I-N.

Numerous similar success stories can be found detailing successful encounters with facilitated communication. Crossley and Biklen are undoubtedly responsible for implementing and reporting the bulk of the qualitative research supporting facilitated communication. Crossley (1988) reported that in a study involving 34 persons with autism or autistic-like behaviors, 23 communicated by spelling sentences, 2 with single words, and 3 displayed no change in ability. Five individuals were lost to follow-up. Biklen (1990) studying another group of Crossley's individuals reported all 21 subjects demonstrated an ability to type single words or sentences. In fact, Biklen reported that as a result of his studies, 90% of all individuals with autism had somehow attained advanced literacy and language skills not apparent before facilitated communication (Green, 1992).

Similar studies have involved not only individuals with autism, but individuals considered to possess varying degrees of mental impairment including those individuals within the severe/profound range. Reported success rates with these individuals are comparable (Crossley, 1992). Biklen, originally quoted estimating as much as a 100% success rate, but since reduced the claim to 90-95% (Rimland, 1992).

Haskew and Donnellan (1992) suggested that the widespread use of facilitated communication is validation itself. These authors' statements indicate that the commitment of time and effort by facilitators to communicate with those individuals experiencing communication difficulties, the volumes of transcripts revealing peculiar dialogue generated from these individuals, and the altered relationships resulting from being able to finally access the thoughts and feelings of these individuals previously alienated from the verbal world, are all adequate justification to validate facilitated communication.

Proponents of facilitated communication appear to demonstrate more religious fervor than scientific sense (Wolfensberger, 1992). Ackerson (1994) described experiencing this belief system while attending a facilitated communication workshop in the fall of 1992. Ackerson possessed little knowledge of facilitated communication and had not had the opportunity to observe facilitated communication in action. During the workshop, sentiment equating disbelief with failure began to surface. Doubters were urged not to attempt facilitated communication, suggesting that, in doing so, their misgivings would be sensed by the client who would feel their intelligence insulted and likely choose not to communicate at all.

Ackerson chose a cautious position, conceding that, given enough time, anyone would probably eventually type some combination of letters that might be construed as something intelligible which, in turn, would allow us to believe a higher level of cognitive ability existed than had originally been thought. However, as the workshop progressed, Ackerson found the skepticism increasing. Ackerson was invited to observe facilitated communication in action. While observing, Ackerson noted an emerging philosophy surfaced promoting the written word as more reliable than the spoken word. Facilitators were advised to disregard any verbal responses and record only responses generated from facilitation.

Ackerson reported an example of verbal skills considered secondary to facilitation was witnessed in the case of Frank, an 11 year old diagnosed with severe mental retardation. Frank possessed some verbal ability. His vocabulary consisted of a few one or two word utterances such as yes, not, and hey you. With facilitation, Frank reportedly produced sentences that conveyed messages such as wanting to pursue a graduate degree. Facilitation also divulged that Frank disliked certain foods. However, when Frank was presented with those foods, he would vocalize more and when asked if they were foods

he liked, he would vocalize yes. Nonetheless, the staff had been instructed to disregard his vocalizations and attend only to his facilitated responses.

In another instance, Frank typed "MEAT EFF." From this communication and a couple of questions eliciting a yes response from Frank, it was determined Frank intended to spell meat and effort which was interpreted to mean it was too much effort for Frank to chew his meat. Frank was served his meat ground from that point on. This decision was made on a seemingly imaginative assumption and could be considered fairly intrusive.

Mostert (1994), applauding Ackerson's cautious, albeit doubting position of facilitated communication pointed out that there is a tendency to implement new ideas, especially those that are instinctively appealing, long before being relatively convinced they will at least do more good than harm. Mostert emphasized persistence, painstaking investigation, and often repeated failures precede worthwhile, cumulative knowledge. To prove a concept effective, it is best to proceed slowly, building layer upon layer of empirical, interconnected knowledge that will provide consequential, vital answers over time. For as exciting and heartwarming as these case studies may be, they remain anecdotal and lack the hallmarks of empirical research.

One such hallmark of research is that the treatment should not cause harm (Prior & Cummins, 1992). Other hallmarks of empirical research (scientific methodology) include: a) quantitative measures of behavior; b) objective assessment of skills and characteristics of subject upon entering the study (e.g., diagnosis documentation and abilities prior to facilitated communication; c) research designs utilizing experimental control, to protect from bias; d) inter-observer reliability procedures to assure objectivity; and e) implementation of procedures, in this instance, to objectively determine the source of the facilitated communications (Green, 1992). Specifically, the ethnographic case studies, such as the ones conducted by Crossley and Biklen share common weaknesses in methodology. Missing from these studies were criteria for diagnosis and the methods

used to obtain diagnosis, demographic information about the subject, methods to control for contradicting sources of influence pertaining to the typed product, and diagnostic reliability or validity measures (Eberlin, McConnachie, Ibel, & Volpe, 1993).

Perhaps the most obvious weakness in the qualitative research presented is the lack of control for the possibility of facilitator influence. Several recent controlled studies have found that facilitators likely influence facilitated communication output. Eberlin et al. (1993) conducted a study designed to specifically answer two questions. First, do individuals with autism demonstrate unexpected literacy skills or communication skills not previously witnessed when initially introduced to facilitated communication; and, secondly, does the individual demonstrate improved literacy skills following 20 hours of facilitated communication experience and training. These authors provided reliable diagnosis, detailed demographic information, and offered complete methodological information in an effort to better determine clientele who might benefit from facilitated communication.

The subjects involved in the study were 21 elementary and secondary students from a common educational program. Twenty were male. Subjects ranged in age from 11.3 to 20.2. Twenty were diagnosed autistic. One was diagnosed with Pervasive Developmental Disorder. The Childhood Autism Rating Scale had been used for Autism diagnosis. Intellectual functioning ranged from mild to profound mental retardation.

Criteria for participation was based on: a) diagnosis of autism; b) speech therapists' evaluation that the individual might better be served by facilitated communication than their current communication system; c) absence of behavior problems; and d) availability for participation. Ten individuals served as facilitators, ranging in age from 19 to 44. Seven were women. All were volunteers experienced and interested in facilitated communication. All had at least some experience working with individuals with autism.

The study involved testing across four testing sessions. During three of the testing sessions, visual and auditory screening procedures were implemented to ensure that the facilitator was unaware of test questions. The conditions for the four test periods were:

- a) Baseline: to determine the subject's optimum communicative ability prior to the introduction of facilitated communication. Facilitator was not present.
- b) Pretest: with facilitator.
- c) Post-training warm-up test: done with a facilitator following 20 hours of facilitated communication training (no visual or auditory screening).
- d) Post-training test: with facilitator and screenings.

A T-shaped screen was used to visually block the examiner from the facilitator's view thereby preventing the possibility of facilitator reaction to stimuli including gestural or other subtle cues which might possibly be inadvertently transmitted by the examiner. Facilitators wore headphones to prevent them from hearing test questions. Facilitators were to report if they were able to hear or see test questions. Although facilitators reported hearing noise, none reported any ability to identify words. Many of the subjects verbalized answers before typing. Facilitators were not screened from viewing the subject's lip movements.

Dependent measures were administered at baseline, pretest, and post-test. These measures involved the use of the vocabulary subtest of the Stanford-Binet 4th Edition (Thorndike, Hagen, & Sattler, 1986) and a personal interview consisting of 20 questions evolving from yes/no questions to more abstract, open-ended questions. These 20 questions were similar in nature to questions presented in workshops and those used by Biklen and colleagues in studies reporting unexpected literacy and cognitive abilities. Subjects were allowed several chances to answer each question. When four consecutive incorrect responses were given, questioning ceased. Scoring of typed responses was

liberal. The liberal scoring criteria was utilized because it most closely replicated the position of those claiming validity of facilitation.

Procedurally, this experiment followed a sequential path of: 1) extensive facilitation training; 2) facilitator/student rapport building as emphasized by Biklen; 3) baseline testing; 4) initial exposure to facilitated communication (15-30 minutes); 5) the pretest (facilitator screened); 6) 40 half-hour facilitated communication training sessions; 7) the post warm-up test in which facilitators were able to see and/or hear the questions using tests similar to the baseline measurement; and 8) the post-test using the same tests as the baseline and pretest measurements. Only facilitated communication responses were acceptable. Overall the subjects were reported cooperative and their performances was deemed valid. The table below as presented by Eberlin et al. (1993) reports the results of the study.

Questions correctly with facilitated communication skills	0	1	2
Median no. of correct responses	0	0	1

The results of this study indicate that initial exposure to facilitated communication did not produce unexpected literacy or communicative abilities for any of the subjects. This finding is contrary to claims by Biklen (1990) and Hunter (1992) that individuals with autism often successfully communicate at unexpected levels during their first encounter with facilitated communication or the initial facilitated communication consultation. Furthermore, following 40 hours of facilitated communication training, none of the students showed improved or emerging communicative skills beyond already established skills. Finally, facilitator influence was obvious under the condition where the facilitator was aware of the content of the questions or answers.

Prior to and following this study, numerous similar studies have been conducted for the purpose of determining facilitator influence (e.g., Hudson, Mehta, & Arnold,

Table 1

Correct Responses Using Facilitated Communication

	<u>TEST PHASE</u>			
	<u>Baseline</u>	<u>Pre</u>	<u>Post</u>	<u>Post Warm-up</u>
No. of subjects with zero correct responses	5	19	15	10
No. of subjects with 1 or more correct responses	16	2	6	11
No. of subjects with 2 or more correct responses	14	2	2	6
No. of subjects who answer more questions correctly with facilitated communication than with pre-facilitated communication skills	—	0	1	2
Median no. of correct responses	8	0	0	1

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Prior to and following this study, numerous similar studies have been conducted for the purpose of determining facilitator influence (e.g., Hudson, Melita, & Arnold,

1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Wheeler et al., 1993).

These studies involved not only individuals with autism, but individuals with a variety of other disabilities as well. Most studies replicate the conditions in the Eberlin et al. (1993) study utilizing visual and auditory blocks to protect from facilitator influence and provide ample opportunity for communication via facilitation. All research has been conducted following the strict guidelines of scientific research designs. The findings overwhelmingly support not only the presence of facilitator influence, but suggest facilitator control (Wheeler et al., 1993). Rimland (1992) described testing conducted at the O. D. Heck Developmental Center in Schenectady, New York. The O. D. Heck professional staff were among the first and most positive supporters of facilitated communication following their attendance at FCT workshops in Syracuse, New York. In an effort to suppress skepticism, this staff suggested arranging an airtight study involving videotaping of the entire experiment. It was believed to be a foolproof, definitive study. The program consisted of 48 individuals with autism. Of that 48, the 12 individuals considered to be most experienced and skilled in facilitated communication and who had used facilitation successfully for 5 to 12 months, were selected to participate. These 12 individuals worked with nine facilitators who they customarily worked with on a daily basis. The experimenters were aware of the characteristic often described by supporters of facilitation, claiming that persons with autism are often reluctant to be tested. They explained their study and not only received complete assurance of cooperation by both the facilitators and the individuals with autism (through facilitation), but also received a thank you for the opportunity to participate.

The study design involved the facilitator and client sitting side by side. A partition was provided to prevent the facilitator from seeing what the client was viewing and vice-versa. Each was shown a picture of a common object. The client's objective was to type the word describing the object (e.g., foot, keys, shoes, etc.). The only time

the client typed the correct response was in the instance when the facilitator and the client were shown the same picture. In fact, when the two pictures differed, the client under the guidance of facilitation sometimes typed the response appropriate for the facilitator's picture. The experimenters had no choice but to conclude that the facilitator was directing the responses of the communicator and facilitated communication did not work.

A summary of controlled evaluations offered by the Autism Research Review International (Green, 1993) indicated that of 35 studies conducted (285 subjects) only six (11 subjects) report confirmed facilitated communication and 29 (274 subjects) indicated the failure of facilitated communication. Confirmed facilitation indicates minimal naming responses, usually only one word.

Despite the clear evidence of facilitator influence, facilitators can be intensely defensive of their methods. Often facilitators are able to provide definitive interpretation of responses which appear unintelligible or random to others (Ackerson, 1994). The evidence provided through qualitative research is often compelling enough to permit well educated professionals, adept in the area of scientific research, to doubt the scientific method (Duchan, 1993).

Proponents of facilitated communication have established many defenses, echoed by all. To explain communication with only one specific facilitator, supporters propose individuals have elected not to prove themselves to others. Crossley and Remington-Gurney (1992) suggested an unskilled facilitator could make it impossible for a competent client to produce any message. When asked to explain how it is possible to type without actually making eye contact with the typewriter or alphabet display, it is mentioned that these individuals possess superb peripheral vision and/or extraordinary spatial memory that allows them to virtually look anywhere and still be able to accurately access the keyboard or alphabet display (Rimland, 1993). Random typing, unintelligible to most and known as garbage typing is described as the client goofing around (Ackerson,

1994). If asked why clients are unable to perform simpler programming objectives (e.g., eye-gazing), supporters offer that those exercises are beneath the client's cognitive level.

Crossley (1992), in rejecting the use of formal testing strategies, maintained that testing procedures have been marred by the absence of Augmentative and Alternative Communication (AAC) professionals. Yet, those same standardized tests have been used in conjunction with facilitation to indicate a rise in intellectual percentile ranks.

A study conducted in 1993 (Calculator & Singer, 1993) involved five students being administered the Peabody Picture Vocabulary Test (PPVT-R) with facilitation and without. Three of the five students showed marked improvement with facilitation. Two of the students performed in the 99th and 95th percentiles with facilitation even though their testing without facilitation failed to yield a percentile ranking. Comparatively, the age equivalents for these two individuals rose from 1.9 and 2.6 to 9.3 and 18.1, respectively, with the use of facilitation. Caution is given, however, considering the facilitator's opportunity for influence is extremely great in this situation. Obviously the facilitator is not only aware of the questions, but also the answers.

There is no evidence that facilitators willingly or knowingly influence their clients or are even aware that they do (Wheeler et al., 1993). It is possible that this influence is derived from a sincere desire by a variety of professionals for the individual with the disability to possess more abilities than they actually have (Shane, 1993). Another likely component is that facilitators have fallen victim to strong, compelling propaganda that facilitated communication is a legitimate technique resulting in an unintentional control of the client's communication (Shane, 1993).

Good intentions notwithstanding, belief in facilitated communication is not an adequate motive when considering that recent, carefully structured scientific research essentially discredits facilitated communication. A forceful resolve to act solely on a belief system can potentially destroy all those good intentions of families and

professionals while slowly eroding any credibility special education has thus far managed to establish (Mostert, 1994).

Facilitated communication spread like wildfire, but its embers seem to be quickly dying. DEAL Communication Centre has closed, void of government support and funding. Current status in Victoria, Australia, indicates there are no programs continuing to use facilitated communication for students with autism. Facilitated communication remains available to some special education and adult programs. Some parents continue to use it, but many have become disenchanted. Organizations are striving to mandate that facilitated communication not be allowed to effect life changing decisions (Green, 1992). Individuals with SCI argue the duty is always to communicate choices, needs, and desires. Facilitated communication, on the surface, offered hope of liberating these individuals from their world of silence. Supporters, caught up in the excitement, eagerly embraced facilitated communication as the answer rather than pursuing it as a possible technique subject to careful scrutiny and testing. As a result, chaos ensued.

Facilitated communication is based on the premise that persons with severe intellectual limitations are capable of complex, abstract thoughts. Supporters, fueled by a sincere desire to access those thoughts and reveal a world full of choices to their clients, eagerly pursued its efficacy, offering case study after case study of successful facilitated communications. Literary skills are seemingly ignored completely, suggesting spelling books are not prerequisite to spelling ability. Sequential methodology is discounted, suggesting the components of sequential research actually result in a communicative breakdown.

Supporters strongly defend their approach to facilitated communication. When presented with documented cases of facilitated communication failure, explanations given include the communicator was not ready, either with the facilitator, the communicator chose not to communicate because they did not feel the need to prove themselves to others, and/or the testing procedures were not conducive to the communicator. However, for every defense offered by proponents of facilitated communication, a counter argument can be offered, and often the alternative explanation has roots in

Chapter III

SUMMARY AND CONCLUSIONS

Individuals with SCI struggle daily in attempts to communicate choices, needs, and desires. Facilitated communication, on the surface, offered hope of liberating these individuals from their world of silence. Supporters, caught up in the excitement, eagerly embraced facilitated communication as the answer rather than pursuing it as a possible technique subject to careful scrutiny and testing. As a result, chaos ensued.

Facilitated communication is based on the premise that persons with severe intellectual limitations are capable of complex, abstract thoughts. Supporters, fueled by a sincere desire to access those thoughts and reveal a world full of choices to their clients, eagerly pursued its efficacy, offering case study after case study of successful facilitated communication(s). Literacy skills are seemingly ignored completely, suggesting spelling basics are not prerequisite to spelling ability. Empirical methodology is discounted, suggesting the components of quantitative research actually result in a communicative breakdown.

Supporters strongly defend their approach to facilitated communication. When presented with documented cases of facilitated communication failure, explanations given include the communicator was not comfortable with the facilitator, the communicator chose not to communicate because they did not feel the need to prove themselves to others, and/or the testing procedures caused undue stress for the communicator. However, for every defense offered by proponents of facilitated communication, a counter argument can be offered, and often the alternative explanation has roots in

careful, scientific research. Scientific research aside, it seems unreasonable to suggest that persons unable to communicate for years would be selective in when, with whom, or under what conditions they would communicate when finally afforded the opportunity to do so.

Clearly, most facilitators do not willingly or knowingly impose their thoughts in facilitated communication output. Generally, their intentions are sincere and their commitment forthright. Scientific research, however, is equally clear in its documentation that facilitator influence indeed exists at a level far exceeding chance.

This author urges great caution when considering facilitated communication, especially if it is recommended as a replacement of verbal skills already in place. The potentially destructive nature of some of the commonly reported messages is another facet of facilitated communication warranting careful consideration. Certainly mistreatment of any kind is reprehensible, but accepting facilitated communications as unquestionable truth may be equally as criminal. Allowing life changing decisions based solely on facilitated communications could result in a type of mistreatment inflicted from a different angle. The original intent of facilitated communication to offer opportunities to make choices may, in fact, be denying that opportunity by allowing the facilitator's wishes to be acted upon. If an individual is to speak for another, as facilitation now seems to imply, it is essential to establish those translations are undeniably accurate.

Facilitated communication may be a viable alternative for some individuals. It is necessary, however, to first identify those individuals by means of careful scientific methodology, providing clearly defined selection criteria. Research does not currently support facilitated communication as a valid or valuable technique for individuals with autism and/or moderate to severe mental impairment.

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