12-6-1995

An Investigation Into Attitudes Surrounding Facilitated Communication

Jessica N. Peregoy
Longwood University

Recommended Citation
Peregoy, Jessica N., "An Investigation Into Attitudes Surrounding Facilitated Communication" (1995). *Theses, Dissertations & Honors Papers*. 534.
https://digitalcommons.longwood.edu/etd/534

An Investigation Into Attitudes Surrounding Facilitated Communication

Jessica N. Peregoy

Longwood College

This thesis was approved by:

Dr. Meese Ruthlyn Meese

Dr. Overton Terry Overton, Ed.D.

Dr. Keith Keith

Dr. Mossler

Date of Approval December 6, 1995

Running Head: COMMUNICATION

Abstract

This qualitative study investigated facilitators' opinions regarding facilitated communication (FC). Six individuals who have experience and/or training in the use of this method were interviewed. Issues discussed included FC's effectiveness for individuals other than those with autism, training prior to using the method, need for modifications in the method, and validity of the communication arising from the use of FC. Recurring themes were constructed from comments made during the course of the interviews. Each theme was supported by comments made by at least half of the facilitators. These themes were dissatisfaction with formal training, application to other populations, acknowledgement of facilitator influence, need for a support network and need for multiple facilitators per student.

Acknowledgments

First, an enormous THANK YOU to all the facilitators who participated in this study. I am extremely grateful for your taking the time to meet with me and tell me about your experiences.

Mom and Dad, you two have been the best parents I could have asked for. Your love and support have given me the courage to reach for my dreams, no matter how unusual they may seem to you at times. I love you two more than anyone in the world. Thank you for being you.

I would also like to thank all the members of my thesis committee for their help and guidance during the last year.

I want to give an extra thank you to two very special members of my committee, Dr. Meese and Dr. Mossler. You two went above and beyond the call of duty as my advisors. You showed confidence in me when I didn't have confidence in myself. You were always willing to talk with me when I had problems or doubts, and listened patiently when I sat in your offices and cried because things just weren't going right. I will always be thankful that I had the opportunity to get to know you as teachers and as friends.

Dr. Simmons, you will be one of the most difficult people to leave. I am grateful that I was given the opportunity to work with you as your graduate assistant. Though I never took one of your classes, you have taught me so much. You are a professional of the highest quality, and a role model for teachers everywhere. Thank you for being so wonderful.

Thanks also to Dr. Whitfield. You are a great teacher and a wonderful person. I enjoyed every minute that I got to work with you and know you over the last year. I am also glad that you have been pleased with my work as a graduate assistant, but please don't fail me! I have to leave sometime!

Dr. Apperson, thank you for being a wonderful teacher and for being there for me when things weren't going so well in my life. Just having someone like you who was willing to listen helped more than anything.

And, last but not least, thank you to all the ladies of the library. You put in a lot of hard work for everyone here at Longwood and too often it goes unnoticed. You have always been extremely helpful and friendly, and we appreciate all you do.

Table of Contents

Appendices

Tables

An Investigation Into Attitudes Surrounding Facilitated Communication

Introduction

Communication can take many different forms. It may be in the form of speech, gestures, non-speech sounds, or body language. Despite its many different forms, communications of any kind all have one thing in common. All communication plays a vital role in establishing and maintaining relationships of any type. When there are barriers to communication, a relationship often suffers. What happens, then, when speech and communication are affected adversely by disorders such as autism? When this happens, several problems arise. One major difficulty is that it is difficult to determine the wants and needs of the impaired individual. Consequently, the individuals may find themselves misunderstood and may experience frustration at the lack of control they have over the situation.

Augmented communication is a way of helping individuals with little or no speech communicate through the use of some type of communication device. This may be a keyboard, a card with letters or words, or a picture board. A new and controversial method of augmented communication, known as facilitated communication (FC), has been developed and investigated in its relationship to autism. The assumption behind this method is that autistic individuals may have higher intellectual abilities than previously thought, and can exhibit these abilities if given the proper equipment. In this method, autistic students are trained to work with a facilitator to type messages in response to questions, or carry on conversations with speaking and other non-speaking people. Since its introduction, this method has received a great deal of attention, both positive and negative. The central issue revolves around whether the students are actually doing the communicating, or if the facilitators are somehow influencing the output. This has raised doubts in the minds of many investigators as to the validity of this type of augmented communication. The arguments against this method are as strong as the arguments for it. Because opinions are so strong on both sides of the issue, they can, and sometimes do, influence the perceived effectiveness or non-effectiveness of FC.

Since the use of facilitated communication is such a controversial issue, educators must recognize the amount of influence personal feelings can have on its effectiveness. The teachers of these children are the ones who are generally the most involved in this type of communication. They are the ones who are usually trained as facilitators and who must gain the trust of the students and their families. They are also the ones who must interpret any messages they may receive from this method and relay the information to family members and other professionals. If they are biased in any way, the education of the students may be compromised.

Overview of Autism

Autism is a puzzling disorder. Though autism has been researched and discussed for over forty years, research regarding this disorder is still in its infancy. The causes are not known, an effective treatment is not known, and most especially, the cure and/or prevention is not known.

In 1943, Leo Kanner published an article discussing eleven children who he had been treating for five years. The children discussed in his article had a disorder that Kanner called "autism." The word autism had been used years earlier by Eugen Bleuler to describe people who had intentionally withdrawn from the external world and reality (Donnellan, 1985). When Kanner used it, he was describing a disorder in which the children were withdrawn from the outside world, but not necessarily intentionally (Donnellan, 1985). Since that time, autism has been called many other names, including: symbiotic psychosis, atypical ego development, and childhood psychosis and emotional disturbance (Hinerman, 1983).

Although autism has been recognized as a disorder for over five decades, the causes of the disorder are still being debated. Early studies attempted to prove that autism was caused by cold, unaffectionate parents who were unresponsive to their child's needs. These studies compared parents of autistic children to parents of "normal" children. The studies failed to find any significant difference between parenting styles of the two groups of parents. The only difference found was that parents of autistic children tended to be more intelligent, better educated, and in a higher occupational level than parents of non-autistic children (Wing, 1972; Schopler & Mesibov, 1984). In his book, Infantile Autism, Bernard Rimland "laid to rest the ghost of psychogenesis so persuasively that no serious behavioral scientist has raised it again (Donnellan, 1985, p. 5).

Once the question of "psychogenesis" was settled, researchers began looking for biological causes of the disorder. Interestingly, when Kanner (1943) first published his report on autism, he suggested that there was a biological basis for it. It was not until 20 years later, though, that Bernard Rimland again proposed that autism was a biological disorder based on his evidence from twin studies (Courchesne, 1989). However, the exact mode of transmission is difficult to determine due to the fact that most autistic individuals neither marry nor have children. Consequently, the only way to study the role of familial transmission is through the use of twin studies (Silliman, 1989).

Although the causes of autism are still somewhat of an enigma, the symptoms are quite clear. Leo Kanner was the first to describe the disorder, and parts of his definition are still used today. Kanner's definition included: lack of human relatedness from the beginning of life, disordered language, and insistence on repetitive behaviors (Schopler & Mesibov, 1984). The society for Children and Adults with Autism also describes a range of behaviors present in autism. These include: slow development or lack of physical, social, or learning skills; immature rhythms of speech, limited understanding of ideas, and use of words without the usual meaning to them; abnormal responses to sensations (i.e. sight, hearing, touch, pain, balance, smell, taste- any one or a combination of these responses may be affected); and abnormal ways of relating to people, objects, and events (Hinerman, 1983). Ornitz and Ritvo listed characteristics of autism as: perceptual disturbances; disturbances of developmental rate; disturbances of relating; disturbances of speech and language; and disturbances of motility (cited in Hinerman, 1983). The

American Psychological Association (1987) describes autism as a pervasive developmental disorder. The diagnostic criteria it describes are qualitative impairment in reciprocal social interaction; qualitative impairment in verbal and nonverbal communication, and in imaginative activity; markedly restricted repertoire of activities and interests; and onset during infancy or childhood.

One of the primary characteristics of autism is a lack of, or delayed, speech and other communication problems. These problems are thought by some to be the result of damage to neurological systems that control motor and cognitive functions (Biklen, Morton, Gold, & Swaminathan, 1992). Autistic individuals who have no speech are generally thought to be "lower functioning" and those with speech are categorized according to the amount and nature of their utterances (Biklen, et al, 1992). Among the communication problems exhibited by autistic individuals are an inability to speak words; speaking with echolalia or repetition of words or phrases heard previously; pronomial reversals; difficulties with social interaction; and seeming unresponsiveness to external events (Biklen, & Schubert, 1991). Another characteristic of some autistic individuals' communication is hyperlexia. Hyperlexia occurs when children show decoding skills and word recognition skills either at a very early age or above those expected for the students' assumed level of intelligence (Biklen, & Schubert, 1991). Hypergraphia also often occurs in autistic individuals. Hypergraphia describes writing abilities that are above those expected for the person's assumed intelligence. Individuals exhibiting these abilities are not much different from those who have echolalia, because both lack "higher-level comprehension" (Biklen, et al, 1992).

Echolalic speech is a common behavior associated with autism. Echolalia is when individuals merely repeat what has been said immediately before their response. Autistic individuals may also exhibit delayed echolalia, which occurs when they repeat statements that were made at some time in the past. Researchers have commonly thought that this type of speech had no communicative significance. However, recent research suggests that this is not true (Biklen, et al, 1992). As early as 1981, Prizant and Duchan identified seven different categories of echolalic speech. These were - "...'turn-taking', 'declarative', 'request', 'yes-answer', 'non-focused', 'rehearsal', and 'self-regulatory'..." (Prizant & Duchan, 1981, p. 249). In 1984, Prizant and Rydell added six more categories: "...'providing information', 'verbal completion', protest', 'calling', 'self-directives', and 'directives'..." (cited in Biklen, Morton, Gold, & Swaminathan 1992, p. 4). For those who do not exhibit speech, Prizant and Schuler (1987) have suggested that many of their physical behaviors may have communicative intent. Among these behaviors are crying, tantrums or aggression, moving toward a listener for attention, gazing at objects, pointing, shaking one's head for refusal or protest, and pulling others to an object or location.

Despite these supposed communicative gestures, however, it is often difficult, if not impossible, to understand the communicative intent of autistic individuals. It is also especially difficult to test the intelligence levels of these individuals since most intelligence tests rely on some degree of verbal ability. Because of these problems, researchers have begun to explore ways of helping autistic individuals communicate.

History of Facilitated Communication

In the 1960s, two pediatricians encouraged more than 60 autistic students to type out messages on Edison Response environments (i.e. talking typewriters). In 1974, Oppenheim worked with autistic students also, providing hand over hand support in her efforts to help them with their handwriting. In the 1980s two parents discussed their work with their autistic son in typing out messages on an electronic keyboard. Shortly after, two more parents reported that they had also taught their son to type messages on a keyboard. Crossley, however, was the first to use the term facilitated communication to describe her method of augmented communication (Biklen & Schubert, 1991).

While working at the St. Nicholas Institution in Melbourne, Australia in the 1970s, Crossley used a type of augmentative communication device to help students with cerebral palsy gain better control over their movements, slow them down, and increase their likelihood of hitting an intended target (Biklen, 1990). Crossley called this method facilitated communication and described it as "a teaching strategy used with people with SCI (severe communication impairments) requiring aided communication who are not yet able to access a communication aid independently" (Cited in Sabin & Donnellan 1993, p. 200). After observing her perceived success with students with cerebral palsy, she began trying the method with autistic individuals. Crossley recognized that some of the problems exhibited by students with autism had also been exhibited by her students with cerebral palsy, and hoped her method would work as well with the new group of students (Biklen, 1990; Biklen & Schubert, 1991;

Biklen, et al. 1992). This method led to some controversy, because it involved the use of hand or arm support. Some believed that the students were not actually choosing the letters, but were being influenced by the facilitators (Biklen, 1990). Crossley reported success, however, when she performed message passing tests. These tests involved Crossley leaving the room and returning to facilitate communication about events occurring during her absence. Following these tests, the Supreme Court of Victoria recognized the communication as coming from the students; so she continued her efforts (Biklen, 1990; Biklen & Schubert, 1991). Since that time, several investigations into the method have been undertaken in order to prove or disprove its effectiveness.

Components of Facilitated Communication

FC involves three main components: a nonverbal or verbally delayed student, a facilitator, and some sort of communication device such as a keyboard or picture board. In this method, students who have problems communicating are given physical and emotional support to "access communication devices" (Sabin, & Donnellan, 1993). Students using this method are able then to type out messages or answer questions. It is not necessary for the students using this method to have any prior literacy training (Regal, Rooney, & Wandas, 1994).

Physical support may range from isolating the index finger to a gentle touch on the shoulder or leg of the student. The purpose of the physical support is "...to help stabilize the arm, to isolate the index finger if necessary, to pull back the arm after each selection, to remind the individual to maintain focus, and to offer emotional support and encouragement..." (Biklen, 1992, p. 243). The idea is to lessen the stress caused by existing physical problems, and focus more on the actual communication of the student (Duchan, 1993). Facilitators are warned against trying to guide the students' movements so that the communication is that of the students and not the facilitators (Duchan, 1993). Physical support varies among individuals. Some need very little support at all, while some may need full body support. The goal is to provide as little physical support as possible so that the students becomes competent at communicating on their own. Facilitators generally provide a great deal of physical support at the beginning, then decrease the support over time. This fading is usually done as soon as possible, but only according to the student's needs. If done too soon, fading may lead to problems in communication (Biklen, et al, 1992).

In addition to physical support, the facilitators must offer emotional support. The student must feel as though he is working with a person who considers him competent and is not trying to test him (Biklen, 1990). When students feel as though they are being tested, communication between the facilitator and student becomes strained (Duchan, 1993). Students often have doubts about their own competence, but when they feel as though they are able to trust their facilitator, and are treated as competent communicators, then they are able to break down the communication barriers (Duchan, 1993). This is the reason given for students generally working best with one facilitator. Biklen and Schubert (1991) give six main elements of FC. These are as follows:

1. Physical support
2. Initial training/introduction. Students are asked to point to suggested pictures on a picture board.

3. Maintain focus. This helps the student refrain from "extraneous actions" and focus on the task at hand.
4. Avoid testing for competence.
5. Set work. Highly structured activities such as fill-in-the-blanks questions.
6. Fading physical support over time. May take months or years. (pp. 46-47)

After these main components are met, facilitators and students develop their own methods according to their own needs and abilities. In their training manual for becoming a facilitator, Barker, Leary, Repa, and Whissel (1993) describe the individual differences this way: "There needs to be a lot of research done to determine which components are critical for success... [til then] you'll just have to learn like the rest of us, by trial and error" (cited in Sabin, & Donnellan, 1993, p.201).

Controversy Surrounding Facilitated Communication

Obviously controversy surrounds facilitated communication, but this controversy can be broken into two main arguments that stem from former beliefs about autism and beliefs about one of the critical components of FC. First, many people have problems with the idea that students who have previously been thought to have limited intellectual capacities are suddenly able to type out complex thoughts and ideas (Cummins, Prior, 1992). The second, and probably largest, concern over this type of communication is that students require some sort of physical support in order to access the communication device. The controversy began shortly after Crossley introduced FC to the world. Skeptics then felt, as they do now, that facilitators were influencing the output of the students (Biklen, 1990). This perceived problem has been the main source of controversy since then.

Duchan (1992, p. 1109) pointed out that when observing FC, "it is difficult to determine visually the origin of movement...because the hands of the facilitator and the FC user's move together." She listed seven occasions when the authorship of the messages may be in doubt:

> 1. When the user is thought not to be literate or intelligent enough to create such a message;
> 2. When the user cannot create messages without the help of the facilitator;
> 3. When the user can communicate only with certain facilitators;
> 4. When message formulation loses intelligibility if a facilitator does not know what the user is about to type;
> 5. When the messages being created are difficult to believe, such as those involving disclosures about physical or sexual abuse;
> 6. When message content requires life changes such as requests for changes in daily programming, or in residential or educational placement.
> 7. When the FC user has trouble creating messages under experimental conditions in which the facilitator is made "blind" to what the user is being asked. (p. 1109)

One of the main problems opponents have with FC is that students who were previously thought to have limited intellectual functioning are now showing incredible literacy skills. Some individuals who were previously thought to be severely and profoundly mentally impaired have been mainstreamed into normal classrooms where they use FC to communicate (Smith & Belcher, 1993). Prior and Cummins (1992) express concern that families of autistic individuals may be uncritically adopting the method of FC because they want to believe that their autistic family members are able to communicate normally. They suggest that such vulnerability on the part of the families makes it difficult to get them to review real data concerning the validity of the method.

In addition, in their critique of an article by Biklen, Cummins and Prior (1992) expressed their disbelief that autistic students who have previously been shown to have low intellectual capacity, could carry on highly intelligent and insightful conversations. This issue was raised again by Eberlin, McConnachie, Ibel, and Volpe (1993). They maintain that during their study, no student showed literacy above that which was expected. They indicate that even after 20 hours of FC training, none of the students showed unexpected literacy or communicative abilities. Smith, Haas, and Belcher (1993) found that no subjects in their study showed evidence of first-time literacy. Similarly, Smith and Belcher (1993) found that the subjects in their study produced typed communication that was equal to their verbal abilities. Those who had no verbal abilities typed only random letters. They contend that the apparent success of FC with verbal individuals might be mistakenly generalized to nonverbal individuals. In contrast, Moore, et al. (1993) found that one of the subjects in their study who had verbal abilities was able to identify verbally all items shown to him in the study, but could not type them using facilitated communication. Prior and Cummins (1992) contend that beliefs of sudden intellectual breakthroughs in conjunction with FC could "...sabotage other educational programs, and may result in the generation of expectations which the autistic person is unable to meet in everyday life." (p. 335) Furthermore, Levine, Shane, & Wharton (1994) indicated that the preferences supposedly typed out by the client may actually be contradictory to what that individual actually wants. They maintain that any changes made for the individual that are not consistent with what the individual actually wants are a violation of the rights of people with disabilities. In addition, many useful forms of communication have been removed from individuals based on the findings of proponents of the method. Levine et al. point out that certain individuals "may be deprived of their independent means of communication" based on the results of these studies (p.302). Finally, Levine, et al. show concern that money and time spent on implementing facilitated communication in the schools is money and time that will not be available for things such as computers, community integration programs, etc. Jacobson found that "approximately $132 million will be spent per year by the educational system on FC and other related activities." (cited in Levine et al., 1994, p. 302).

Problems with the student typing messages alone are also reported in the literature. Prior and Cummins (1992) indicate that many students who have clearly had the motor skills to access a communication aid effectively have still had to have physical support in order to use FC. In 1993, Sabin and Donnellan describe an instance when one of their subjects announced he was going to type alone. When he attempted to do so, however, he typed only random letters. When a facilitator offered support, he was again able to type. Biklen (1992) indicated that one of the reasons for the need for physical support was to "...pull back the arm after each selection..." (p. 243). However, Smith and Belcher (1993) suggest that any use of error prevention such as this dramatically changes the nature of facilitated communication. If a subject is prevented from making incorrect responses, the communication is of course going to be near perfect. Over time, the person being corrected learns which responses are allowed to which questions.

In 1990, Biklen indicated that it has often been difficult for students to communicate with more than one or two facilitators. Cummins and Prior (1992) also pointed out that subjects in Biklen's 1990 study failed to communicate with other facilitators even though the others had a strong desire to work with the students. Smith, Haas, and Belcher (1993) found that facilitators do not need extensive training in order to be considered competent in FC. They note that a one day workshop is considered sufficient training for a facilitator to be able to use the method. They also point out that the workshops often heavily stress the breakthrough effect of the procedure. Similarly, Prior and Cummins (1992) point out that in order for the method to work, expectation, enthusiasm, and commitment are required. They state that those with neutral or skeptical attitudes have had difficulty in using the method.

In 1993, three court cases arising from charges of sexual abuse made by students using FC found that the communications were not from the students but rather were from the facilitators (Bligh, Kupperman, 1993; Heckler, 1993; Hudson, Melita, & Arnold, 1993). Hudson, et al. suggested that if the people making the allegations were actually able to communicate using FC, they would surely want to prove that they could use the method effectively. However, none of the allegations held up under scientific scrutiny. Similarly, Cummins and Prior (1992) expressed concern over the statements made in Biklen's 1990 study where students expressed ideas as to how individuals with handicaps should be treated. Prior and Cummins (1992) contend that many parents have been made to feel guilty over these years of supposed misunderstanding.

Bligh and Kupperman (1993) found that when their subjects were communicating, and the facilitators were unaware of the answers to the questions, the responses made no sense. Bligh and Kupperman also found that when their subjects typed messages to questions seen only by the student, the messages were unintelligible. Similarly, Moore, Donovan, Hudson, Dykstra and Lawrence (1993) found no appropriate responses when the facilitators were unaware of the questions asked. Smith, Haas, and Belcher (1993) found similar results in their study. They provided three levels of facilitator support in their study: no help, medium support, and full support. Under the no help condition, no correct responses were made, and only one correct response was made in the medium support level. However, in the full support condition, there were a significant number of instances where correct responses were recorded. Vazquez (1994) expressed concern that the studies done to date have not been indicative of communications in natural situations due to the use of headphones, screens, or unfamiliar facilitators. Because of this, she took efforts to preserve validity in her study by not providing any unnatural circumstances. Her results still showed that correct answers overall were only typed when the facilitator knew the answer to the question. Routh (1994) went so far as to accuse facilitators of treating individuals with disabilities as "ventriloquist's dumm[ies]" (p.675). All of these studies indicate that there are considerable problems in determining the effectiveness of facilitated communication. Few of these studies reported any success at all with FC. Most indicated that the messages were undoubtedly those of the facilitator, and not the student.

Support for FC, however, is just as strong as arguments against it. Most of the investigations into the effectiveness of this method are qualitative studies. The reason for this is that FC proponents fear that if the method is empirically tested, the investigations would "violate the bond of trust and acceptance that an FC relationship requires" (Regal, Rooney, & Wandas, 1994, p.346). In these studies, close observations are made of individuals in their natural environment.

Smith and Belcher (1993) suggested that FC was developed in Australia, and brought to America by Biklen. Indeed, Biklen (1990, 1991, 1992) has done numerous investigations into the effectiveness of FC. Biklen and Crossley suggested that autistic individuals cannot speak due to problems with voluntary motor control (cited in Ogletree, Hamtil, Solberg, & Scoby-Schmelzle, 1993). Biklen's first report was in 1990 when he published "Communication Unbound: Autism and Praxis." In this report, Biklen described his meeting with students who had been trained in facilitated communication. Though he had considerable doubts at the beginning, Biklen found himself engaged in an intelligent, thoughtful discussion with the students. Biklen stated that what he observed drastically changed his assumptions about autism.

Biklen teamed up with Annegret Schubert in 1991 to report another success story. This time it was a 7-year-old first grader. Biklen and Schubert reported that this student and others had revealed unexpected thinking and literacy skills. They cited Crossley (1988) and Biklen (1990) as hypothesizing that the reason for the seemingly sudden burst in intellectual capacity was due to the fact that typing is a much less complicated activity than virtually every other physical activity the person with autism must perform. Also, many parents have indicated that they had originally attempted to use flash cards with their children but had abandoned that idea when no success was observed. Parents also reported that their children had been exposed to educational television programs that may have enhanced their intellectual abilities. Furthermore, some of the children had been observed skimming through books, possibly picking up more information than previously thought. Wheeler, Jacobson, Paglieri, and Schwartz (1993) point out that if autistic individuals could actually demonstrate high communicative competence, then this would provide them with increased opportunities to become their own advocates.

In 1992, Biklen, Morton, Gold, and Swaminathan (1992) reported success on the part of the students at typing out messages that were coherent and appropriate. In this report also, Biklen et al. address concerns as to the origin of the communications:

1. The style, speed, and accuracy of a student's fine motor control movement to the letters or keys is fairly consistent across facilitators.
2. Individuals make typographical errors that are unique to them.
3. Many individuals produce phonetic or invented spellings

> that are unique to them and do not appear in the work of others, despite the fact that several individuals sometimes share a common facilitator.
>
> 4. Some individuals type phrases or sentences that are unusual and would not be expected from the facilitators.
> 5. Individuals sometimes produce content that is not known to the facilitator.
> 6. Perhaps the most impressive and satisfying, through communication individuals reveal their personalities. (p. 19-21)

Biklen also reported that many of the students he had observed have become more and more independent over time. Some have even become totally independent (Biklen & Schubert, 1991; Biklen, 1992). Biklen has suggested that more than 90% of individuals with autism may be able to use FC successfully (Smith & Belcher, 1993).

Ogletree, Hamtil, Solberg, and Scoby-Schmelzle also found evidence of independent communication in their 1993 study. The student in this study engaged in free-play activities with a graduate assistant while his facilitator (i.e., his mother) was absent. When the facilitator returned, she asked the student questions about what had happened during free-play. Ogletree et al. observed that using FC, the student was able to describe activities he had been engaged in while his mother was gone. Similarly, Vazquez (1994) found that though overall her subjects could not type independently, one of them did show some evidence of independent communication. On five blind trials, the subject correctly answered questions posed to her with the help of a facilitator. On 3 other blind trials, she pushed the facilitator away and was able to type independently.

Calculator and Singer (1993) reported some interesting findings on the change in scores on intelligence tests using FC. They administered the Peabody Picture Vocabulary Test-Revised to five subjects with and without facilitation. Facilitators wore ear plugs and headphones to prevent their interference. Calculator and Singer found that while using FC, four of the students showed improved performance on the test. (Ogletree, Hamtil, Solberg, & Scoby-Schmelzle, 1993).

Proponents argue that even if the communication is somehow influenced by the facilitator, this should not be considered a problem. In 1992, Donnellan, Sabin, and Majure pointed out that in any type of communicative interaction, partners influence one another's behavior. They maintain that communication is a collaborative effort, with each partner taking cues from the other. Duchan (1993) expressed the same idea. She stated that partners work together to accomplish communication goals. They provide verbal and nonverbal cues that help to guide the conversation. Duchan cites evidence from numerous studies that indicate that collaboration also occurs in nonverbal communications. This type of collaboration helps to create "mutual understanding" (Higginbotham, cited in Duchan, 1993, p. 1111). Vazquez (1994) proposes that if we look at FC as a way of developing linguistic and cognitive skills over a period of years, then cueing should be seen as a natural part of that process. Furthermore, Levine, Shane, and Wharton (1994) argue that even if people believe communication arising from this method is invalid, FC continues to have many benefits. Its main benefit is a more positive view of the populations with which it is used. This view could lead to programs being developed to address self-stimulatory behaviors, and participation of the target populations in more meaningful activities than previously experienced. Kaiser (1994) also suggested that the people who work most closely with these individuals perceive that they are vulnerable to abuse and become aware of the frustrations of people with severe physical impairments. Kaiser points out that this population is especially vulnerable to maltreatment due to their limited communication skills. Levine, et al. also point out that when facilitated communication is used, previous behavior problems often decrease.

Statement of Purpose

One of the problems many people still have with FC is that there are seemingly very few formal research studies indicating its effectiveness. This has caused some to believe that since the method has not been extensively empirically tested, it is not valid. Consequently, more research studies are being performed to test this method and attempt to prove that it can hold up under scientific scrutiny. In his response to Cummins and Prior, Biklen noted that in his 1990 study, students using FC were given a gift while their facilitators were not present. When the facilitators returned, the students were asked about the gifts they received, and they all answered correctly (Biklen, 1992). Ogletree et al. (1993) indicate that scientific research studies up to this point have not been "ecologically valid" (p. 1) They point out that many of the studies have used artificial physical barriers and headphones to try to validate the method, and that these conditions are not commonly present in normal FC conversations. Furthermore, Donnellan et al. (1992) discussed scientific study as not being immune to attitudes and opinions. Even though we must be aware and responsive to "scientific skepticism" (p. 79), we do not have to ignore the results of previously observed events. Donnellan et al. suggested that there is a strong need to continue scientific investigations into FC, but professionals must be careful about letting personal beliefs get in the way of observed facts. Similarly, Ogletree, et al. (1993) suggest that failure to validate FC will continue to divide proponents and skeptics of the method.

Much research still needs to be conducted in the field of autism and facilitated communication. The need for empirical research to evaluate not only the effectiveness, but also the impact on individuals with autism and their families, is evident. Though FC is still extremely controversial, the method has at least made people look more closely at autism and its characteristics, especially the communication difficulties accompanying the disorder. Ogletree at al. (1993) indicate that the parents of the student in their study have begun to look at their child more positively, and have reported a reduction in the child's frustration level and stereotyped behaviors. Whether FC is valid or not, it has certainly accomplished one goal, and that is to challenge our previously held assumptions about the intellectual capabilities of autistic individuals and their personalities.

Clearly proponents and opponents of FC hold strong opinions regarding the effectiveness of the procedure. No studies, however, have examined the perceptions facilitators hold about FC. The purpose of this study, therefore, is to investigate the attitudes held by trained facilitators concerning the validity of facilitated communication.

Method

Subjects

The subjects for this study were six adults who are trained in the use of facilitated communication (FC) and/or have experience using the method. Five of the subjects were female and one was male.

Procedure

The work and educational background of each facilitator was obtained through the use of interviews as were the opinions of the facilitators toward facilitated communication. The interviews were conducted in a private setting so that all information would remain confidential. A standard table of questions was used to conduct the interviews. (See Appendix A) The subjects were informed that the interviews were being audio taped and transcribed so that the investigator could ensure an accurate recording of all responses made. (See Appendix B) Following the transcription, the audiotapes were destroyed.

Reliability

The responses were analyzed for recurring themes across participants. All responses were grouped in categories according to these themes. Accuracy of these categories were verified by two experts in the field of special education who were unaware of the purpose of this study. These experts were asked to group randomly ordered responses in the categories used by the investigator. The experts' categorizing was then compared to the investigator's grouping. Reliability was determined by dividing the number of agreements by the number of agreements plus disagreements and then multiplying by 100 to obtain an agreement percentage.

Results

Subjects

Out of the six subjects, two have Bachelor's Degrees, three have Master's Degrees, and one has one year of college. Only one subject has a license for teaching. The number of workshops attended prior to using the method varied according to each subject. Subject #1 participated in three training seminars; subject #2, one; subject #3, none; subject #4, one; subject #5, one; and subject #6, two. Five out of the six regularly participate in training workshops focused either on facilitated communication itself, or specific disabilities depending on their area of work. The mean number of years using the method was 3.8.

The subjects worked with nineteen different types of disabilities; the most common were autism (n=6) and mental retardation (n=5). These were followed by physical disabilities (n=2), hearing impairments (n=2), Down Syndrome (n=2), and emotional disturbance (n=2). Other populations mentioned included developmental disabilities, long-term mental illness, visual impairments, speech-language problems, cerebral palsy, learning disabilities, other health impaired, at-risk, stroke, severe disabilities, multihandicapped, deaf-blind, and orthopedically impaired. Each of these areas were mentioned by one person.

All six of the subjects have used FC with individuals with autism. Two have used FC with individuals with severe and profound mental retardation, and one each with Down Syndrome, stroke, and physical impairments. Two subjects each used other types of augmented communication devices such as signing, symbols, and picture charts. Pointing to choices on the arm, picture flip books, cued speech, typing without facilitation, pointing without facilitation, concrete objects, real pictures, computer assisted instruction, computer assisted communication, and word boards were each used by one person.

The subjects were a mixture of parents and professionals with varied educational and vocational backgrounds. A short description of each subject follows.

Subject #1

The first subject was a woman in her mid forties with a Bachelor's Degree in English. She has a son with severe autism, with whom she has been using FC for five years. She is currently still using it with her son. In addition to using facilitated communication, she and her son have also used other methods of augmented communication, including pointing to choices on her arm. She indicated that she has worked with special populations not only because her son is disabled, but also to help other parents of children with special needs. Since discovering that her son has autism, she has been attending every workshop that she can in order to learn more about his disorder. In addition to attending conferences dealing with her son's disorder she participates in workshops dealing with mental retardation and severe handicaps. She has also worked with parents of children with special needs.

Subject #2

The second subject was a woman in her forties who is a speech-language pathologist. She also has a background in psychology and behavior management. She is the director of a non-profit foundation whose purpose is to support and help families of children with developmental disabilities. She has been using FC for five years, though currently not on a regular basis.

However, she does have a friend with whom she facilitates when the opportunity arises.

Subject #3

The third subject was a man in his mid-forties with a Bachelor's Degree in Biology. He has a daughter with autism, and has been facilitating with her for approximately three years. He has received no formal training in the use of the method, but has used it extensively with his daughter, and he has been trained in that fashion. He has used the method only with his daughter. He has not worked with any other individuals with special needs, nor used any other type of augmented communication.

Subject #4

The fourth subject is a woman in her forties who works at a parent resource center. She has a son with autism and she has been facilitating with him for three years. Her work with special populations involves doing vocational assessments for students in a special education curriculum in the public schools. She also works with parents who have children in special education, organizing workshops and programs with guest speakers. In addition, she answers questions regarding special populations and services, helps run a lending library, and publishes a newspaper for the parents of children with disabilities. In conjunction with her job, she receives training through the Department of Education and the Parent Educational Advocacy Training Center.

Subject #5

The fifth subject is a woman in her mid-forties who has a Master of Education Degree and a specialization in severe and profound handicaps. In addition, she has a strong background in psychology and human development and has taken courses in language development, augmented communication, behavior modification, and adapting instruction. She is the general manager of a private, non-profit electronics assembly business begun in 1986 for the purpose of employing individuals with disabilities along with non-disabled co-workers. Her business employs nine individuals with developmental disabilities. She has used facilitated communication for three years and she is currently using it.

Subject #6

The sixth subject is a woman in her mid-thirties with a Master's Degree in Education, and a teaching certification in mental retardation and emotional disturbances K-12. She is a consultant to school systems, and her job involves working with whole school systems, individual classes, and individual students. She works in the areas of curriculum, behavior management, communication, and managing health needs. She has taken practica that involved working with children and adults with autism and worked at a summer camp for people with mental retardation. Other background education include classes in diagnostic reading and behavior management.

Procedure

The work and educational background of each facilitator was obtained through the use of interviews as were the opinions of the facilitators toward facilitated communication. The interviews were conducted in a private setting so that all information would remain confidential. A standard table of questions was used to conduct the interviews. (See Appendix A) The subjects were informed that the interviews were being audio taped and transcribed so that the investigator could ensure an accurate recording of all responses made. Following the transcription, the audiotapes were destroyed.

Themes

After the interviews were transcribed, specific themes were constructed by comparing statments that were similar across subjects. In order for a topic to be considered a theme, statements that supported the topic must have been made by at least three (50%) of the subjects. A total of fifty-five responses were found that supported the themes. Following are the constructed themes and examples of supporting statements.

Recognition of Facilitator Influence

Much of the literature on facilitated communication suggests that it is not a valid form of communication for individuals with disabilities. Many people believe that facilitators influence what is being typed by the students. Therefore, this theme was constructed out of statements made by the subjects expressing concern over facilitator influence. This theme had the most support, accounting for 19 (35%) of the total statements. (Table 1) Statements representative of this theme included:

> ...I think it's real important for people using facilitated communication who are the facilitators to be aware that they can influence people...

> I think that there are people that, with all the best intentions in the world, say what they think the person wants to say, and move their hand around.

Need For A Support Network

One of the concerns expressed by the subjects was the fact that they had no other facilitators with whom to consult while using the method. They felt that a support network of facilitators would help in the use of this method. Thirteen

(24%) of the total statements supported this theme (Table 2) including:

...it would have been sufficient had I had a support group and a network around me that I could problem solve and talk about things with...

When you have someone use any method that's new to them or that they use in isolation from anyone else, and they have no support, no one's technical support, no one can help them improve...

Application To Other Populations

Although facilitated communication has been used most extensively with individuals with autism, all of the facilitators felt that the method could also work with other populations. This theme was supported by 11 (20%) of the total statements. (Table 3) Representative statements for this theme included:

...I think it would be neat to try it with people who have had strokes.

I have used this with some individuals with cerebral palsy, individuals who are mentally retarded, people who have oral dyspraxia, or oral dysphasia...

Need For Multiple Facilitators Per Student

A few of the subjects indicated the need for more than one facilitator per student to reduce the chance of influence and offer more support to the students. This theme accounted for 8 (14%) of the total responses. (Table 4) Statements representative of this theme include:

...it's really good to brainstorm and have a whole group of people ...for the person that's being facilitated, so they don't rely on one person so much...

We want kids to be able to communicate with the kids in their classes and not necessarily have an adult around all the time.

Dissatisfaction With Formal Training

A few people interviewed indicated that when they began using FC, the training they had received prior to using the method was inadequate.

Therefore, this theme expressing facilitator dissatisfaction, was constructed. Four (7%) of the total statements were included in this category: (Table 5)

...I went through a lot of training, and for the first thirteen months I was doing it with Matthew, I didn't think I had enough training.

...there needs to be some more kind of organized training, preparation, for teachers and aides, and, well, professionals and paraprofessionals who work with individuals with developmental disabilities.

Reliability

Overall interrater reliability between the investigator and Expert #1 was 100%. Across themes, reliability was also 100%. (Table 6) Overall interrater reliability between the investigator and Expert #2 was 98%. Across themes, interrater reliability was 100% for theme A, 91% for theme B, 100% for theme C, 93% for theme D, and 100% for theme E. (Table 7) Interrater reliability overall between Expert #1 and Expert #2 was 98%. Across themes, interrater reliability between Expert #1 and Expert #2 was 100% for theme A, 91% for theme B, 100% for theme C, 93% for theme D, and 100% for theme E. (Table 8)

Discussion

During the course of these interviews, several comments were made concerning the amount of influence facilitators have on the communication of individuals using facilitated communication. This is consistent with much of the research on FC. Most of the quantitative studies that have been published concerning the validity of FC have found that facilitators have an enormous influence on the resulting communication. This is one of the arguments opponents of the method use to discount the validity of the responses. However, though they acknowledged the existence of facilitator influence, all of the facilitators interviewed said that they do believe the communication is valid in many cases.

Another interesting subject brought up by some of the facilitators was the idea of autism being a movement disorder. This is also consistent with the research. Biklen and Crossley (1990, 1991, 1992) proposed that problems in speech associated with autism are due to difficulty with voluntary motor control. When asked for what populations the method might be valid, a few of the subjects commented that it is difficult to make generalizations across populations because everyone is different. They indicated that what may work for some members of a population may not work for others. One subject made an analogy between the struggle for rights of individuals with disabilities and the civil rights movement. She commented that although we have come a long way in both cases, we still have a lot to accomplish. One of the facilitators mentioned that a goal she needs to accomplish is to stop making generalizations about abilities based on appearances. She concluded that if we stop deciding what people can and can't do based on their disabilities, and begin looking at them as individuals with abilities, we can open them to more opportunities to express themselves. One of those opportunities, she said, is facilitated communication.

This investigation also found inconsistencies with the research. Smith, Haas, and Belcher (1993) suggested that facilitators do not need much training in order to begin using FC. They stated that a one day workshop is considered sufficient training for a facilitator to be able to use the method. However, when asked if the training they received was sufficient to begin using the method, many of the subjects indicated that it was not. In fact, the majority of them described their training as an on-going process of attending worksops in order for them to continue to use the method effectively. The validity of the statements made during the use of facilitated communication was also inconsistent with previous research. Many studies have found that when students are asked questions and the facilitators are unaware of the answers to the questions, incorrect answers are given. However, some of the subjects in this study indicated that they had done their own validation studies and had different outcomes. One individual described a situation when she made up a list of questions that no one but her family could possibly know the answers to and gave them to her son's facilitator to ask. When her son was asked the questions and the facilitator helped him type, all the answers he gave were correct.

Some problems and limitations were involved in this study. Seven facilitators were actually interviewed, but only six were used. One of the subjects had left his previous job where he was a facilitator and was not actively facilitating at the time of the interview. Therefore, the interview was not included in this study. This resulted in a smaller sample size, which may have had some effect on reliability. Another problem arose when the investigator did not take the interview questions to one of the interviews and had to rewrite them a half hour before meeting the subject. Fortunately, all but one of the questions were remembered, and the answer to the last one was obtained over the phone. The investigator also intended to send copies of the interviews to the subjects for accuracy checks, but time ran out, and this was not accomplished. However, because the interviews were audio taped and transcribed verbatim, the investigator is confident of their accuracy.

The researcher was not surprised at the overall results of this study. She was, however, very interested in some of the comments made during the course of the interviews. One subject in particular that seemed to come up with many of the facilitators was the idea of autism being a movement disorder. The researcher would like to see more studies done examining this possibility. If movement is found to be the main problem for these individuals, it would certainly change the way we think about people with autism and the way we plan their educational programs.

The researcher would also like to see more research focused on the facilitators and their experiences with the method. Rather than constantly trying to prove the validity or the invalidity of the method, we should talk to the people who actually use the method and find out what they think. They can offer incredible insight into the process of facilitated communication and what improvements need to be made. The researcher should point out here that going into this study, she was concerned that all of the facilitators would be biased toward this method and would try to convince her of its validity. She was wrong. Not only did all of the facilitators acknowledge the existence of facilitator influence, but most of them also acknowledged that they sometimes influence the statements made by the students. Therefore, studies that focus on the facilitators' experiences can be extremely helpful in determining the effectiveness Of this method and need for improvements.

References

American Psychological Association. (1987). Diagnostic and Statistical Manual of Mental Disorders (3rd ed., revised). Washington, D.C.

Bettelheim, B. (1967). The Empty Fortress. New York: The Free Press.

Biklen, D. (1990). Communication unbound: Autism and praxis. Harvard Educational Review, 60(3), 291-314.

Biklen, D. (1990). Autism orthodoxy versus free speech: A reply to Cummins and Prior. Harvard Educational Review, 62(2).

Biklen, D., Morton, M.W., Gold, D., Berrigan, C., Swaminathan, S. (1992). Facilitated communication: Implications for individuals with autism. Topics in Language Disorders, 12(4), 1-28.

Biklen, D., Schubert, A. (1991). New words: The communication of students with autism. Remedial and Special Education, 12(6), 46-57.

Bligh, S., Kupperman, P. (1993). Brief report: Facilitated communication evaluation procedure accepted in a court case. Journal of Autism and Developmental Disorders, 23(3), 553-557.

Courchesne, E. (1989). Neuroanatomical systems involved in infantile autism: The implications of cerebellar abnormalities. In G. Dawson (Ed.) Autism: Nature, Diagnosis and Treatment (pp. 119-143). New York: The Guilford Press.

Cummins, R.A., Prior, M.P. (1992). Autism and assisted communication: A response to Biklen. Harvard Educational Review, 62(2), 228-241.

Dawson, G., Ed. (1989). Autism: Nature, Diagnosis, and Treatment. New York: The Guilford Press.

Donnellan, A.M., Sabin, L.A., Majure, A. (1992). Facilitated communication: Beyond the quandry to the questions. Topics in Language Disorders, 12(4), 69-82.

Duchan, J.F. (1993). Issues raised by facilitated communication for theorizing and research on autism. Journal of Speech and Hearing Research, 36, 1108-1119.

Eberlin, M., McConnachie, G., Ibel, S., Volpe, L. (1993). Facilitated communication: A failure to replicate the phenomenon. Journal of Autism and Developmental Disorders, 23(3), 507-529.

Gillberg, C. (1990). Autism and pervasive developmental disorders. Journal of Child Psychology and Psychiatry, 31(1), 99-119.

Heckler, S. (1994). Facilitated communication: A response by child protection. Child Abuse and Neglect, 18(6), 495-503.

Hinerman, P.S. (1983). Teaching Autistic Children to Communicate. Maryland: Aspen Systems Corporation.

Hudson, A., Melita, B., Arnold, N. (1993). Brief report: A case study assessing the validity of facilitated communication. Journal of Autism and Developmental Disorders, 23(1), 165-173.

Kaiser, A.P. (1994). Invited commentary: The controversy surrounding facilitated communication: Some alternative meanings. Journal of the Association for Persons with Severe Handicaps, 19(3), 187-190.

Kanner, L. (1963). Autistic disturbances of affective contact. In A. Donnellan (Ed.), Classic Readings in Autism (pp.11-52). New York: Teachers College Press.

Levine, K., Shane, H.C., Wharton, R.H. (1994). What if...: A plea to professionals to consider the risk-benefit ratio of facilitated communication. Mental Retardation, 32, 300-304.

Moore, S., Donovan, B., Hudson, A. (1993). Brief report: Facilitator-suggested conversational evaluation of facilitated communication. Journal of Autism and Developmental Disorders, 23(3), 541-552.

Moore, S., Donovan, B., Hudson, A., Dykstra, J. & Lawrence, J. (1993). Brief report: Evaluation of eight case studies of facilitated communication. Journal of Autism and Developmental Disorders, 23(3), 531-539.

Ogletree, B.T., Hamtil, A., Solberg, L., and Scoby-Schmelzle, S. (1993). Facilitated communication: Illustration of a naturalistic validation method. Focus on Autistic Behavior, 8(4), 1-8.

Prior, M., Cummins, R. (1992). Questions about facilitated communication and autism. Journal of Autism and Developmental Disorders, 22(3), 331-338.

Prizant, B. & Schuler, A. (1987). Facilitating communication: Theoretical foundations. In D. Cohen, A. Donnellan, & R. Paul (Eds.) Handbook of Autism and Pervasive Developmental Disorders. New York: Wiley.

Regal, R.A., Rooney, J.R., & Wandas, T. (1994). Facilitated communication: An experimental evaluation. Journal of Autism and Developmental Disorders, 24(3), 345-355.

Routh, D.K. (1994). Commentary: Facilitated communication as unwitting ventriloquism. Journal of Pediatric Psychology, 19(6), 673-675.

Sabin, L., Donnellan, A.M. (1993). A qualitative study of the process of facilitated communication. Journal of the Association for Persons with Severe Handicaps, 18(3), 200-211.

Schopler, E., & Mesibov, G. Eds. (1984). The Effects of Autism on the Family. New York: Plenum Press.

Silliman, E.R., Campbell, M., & Mitchell, R.S. (1989). Genetic influences in autism and assessment of metalinguistic performance in siblings of autistic children. In G. Dawson (Ed.), Autism: Nature, Diagnosis, and Treatment (pp. 225-259). New York: The Guilford Press.

Smith, M.D., Belcher, R.G. (1993). Brief report: Facilitated communication with adults with autism. Journal of Autism and Developmental Disorders, 23(1), 175-183.

Smith, M.D., Haas, P.J., Belcher, R.G. (1994). Facilitated communication: The effects of facilitator knowledge and level of assistance on output. Journal of Autism and Developmental Disorders, 24(3), 357-367.

Vazquez, C.A. (1994). Brief report: A multitask controlled evaluation of facilitated communication. Journal of Autism and Developmental Disorders, 24(3), 369-379.

Wheeler, D.L., Jacobson, J.W., Paglieri, R.A., & Schwartz, A.A. (1993). An experimental assessment of facilitated communication. Mental Retardation, 31(1), 49-60.

Wing, L. (1972). Autistic Children: A Guide for Parents and Professionals. New Jersey: Citadel Press.

APPENDIX A
INTERVIEW QUESTIONS

Interview Questions

1. What type of degree do you have? Where did you receive it?
2. Do you hold a Virginia teaching license? In what areas?
3. Is your job in any way related to working with special populations?
4. What classes have you taken that pertained to your job?
5. Why did you decide to go in to this type of work?
6. With which special populations have you worked?
7. Are you presently facilitating?
8. Have you ever used any type of alternative communication besides facilitated communication? What type? With which populations?
9. When did you begin using facilitated communication?
10. What information, if any did you have about facilitated communication prior to being trained in its use?
11. What type of training did you receive in order to become a facilitator?
12. Do you feel this training was sufficient? If so, in what way? If not, how could it be improved?
13. With which populations have you used facilitated communication?
14. With which populations do you feel facilitated communication is valuable?
15. What beliefs, if any, did you hold about the effectiveness of facilitated communication prior to using the method?
16. How have your beliefs been affected, if at all, by using facilitated communication?
17. Have you ever been surprised by anything that has occurred while using this method? In what way?

18. Do you believe that the statements made by your clients while you're facilitating are valid? Why? Why not?
19. What modifications, if any, do you feel need to be made in the use of this method?
20. Will you continue to use facilitated communication? Why or why not?
21. When should people consider or not consider using facilitated communication?
22. Do you have any other comments?

APPENDIX B

TRANSCRIBED INTERVIEWS

Subject #1

1. I have a B.A from ______ in English.

2. No.

3. Um, not now, because I'm not employed now. But my last three jobs were working with people with disabilities.

4. What classes? Well, I'm the mother of a young man with severe autism. So, ever since he was diagnosed I've been to just about every professional conference which I could attend. Every year I go to the _________ for the mentally retarded, a conference which is put on in conjunction with the ___ resource center. And um, at one time they were having two conferences a year which pertained to mental retardation and autism. Now the autism conference is just once a year. But I go to that, I've been to the national conferences for TASH, the Association for the Severely Handicapped. I've taken a lot of classes, but, um, first-hand experience has been a great educator too for me. I've also been on the county special education advisory committee for 6 years, under that, we had lots of presentation presented to us about various types of disabilities. I've also had training in something called partners in policy making. Which is sponsored by the ___ Board for People with Disabilities, and we had national speakers come in and train our class, and that was a very intensive year's worth of training there. And then in my various jobs I've had training. One of the things we had was, uh, a certified life training, which is ______, and that's a training to use leisure and recreation opportunities for people with all types of disabilities.

5. Working with people with disabilities? Well, it's kind of what I have the background for, and the training. Uh, my first job with people with disabilities, I was hired as a parent by the community services board, to work with other parents. And that was on a statewide demonstration grant. We were integrating kids with severe disabilities into regular, after school daycare. With the help of one special ed trained person to support children (from/on?) each side. And that was called _____. And I was hired really for my experience as a parent, to talk to other parents, and that's what really (brought out my story more completely, with this.)?

6. Well, I have worked with people with autism, people with mental retardation. Mostly I've worked with children who have been identified, let's see, our county used to use the term trainable mentally retarded, now they use moderately mentally disabled. Um, I guess mostly with that population and people with autism, although some of the projects with

which I worked, we worked with young adults probably in the age range of 18 to 30-something, and they were people with all kinds of developmental disabilities, long-term mental illness, physical disabilities, people who have used wheelchairs, um, people who, um, had hearing impairments, several people who had juvenile rheumatoid arthritis, and uh, individuals who were blind, so, it's been a large population.

7. Yes, every, just about every day with my son.

8. Oh, yeah, and my son talks, it's just that you can get a little more clear understanding of what's going on when we use facilitated communication. Um, by facilitated communication, we don't always use a letter-board. Would you like me to expand on that? There's just times when it's not really appropriate or convenient to sit down and spell out things, so, in order to make quick choices, um, we'll um, use my arm. And, for example, if we're going through a drive-through, and he wants a milk shake, I'll say "What flavor do you want?" And I'll say chocolate is here and strawberry is here. And he can tap which one, he might, whenever you give him a choice, if you say chocolate or strawberry, he'll say the last thing you offered him, he'll say strawberry. If you say strawberry or chocolate, he'll say chocolate. You cant always rely on his voice because he echoes the last word of the phrase. So the way that we do it, is I'll say, "we're going to get a milkshake, which flavor do you want, and I'll point to, 'cause this is on tape, my wrist would be chocolate, and my elbow would be strawberry, so there's a big difference between the two and he has enough room so that he can point independently. So, or we'll say do you want to go shopping at Leggett's, and Leggett's would be my wrist, or at Hecht's, and Hecht's would be my elbow, and he can pick which store he wants to go to. And he does have pretty strong tastes.
(Interviewer-With which populations?)
Well, um, I've facilitated with more individuals than my son. Um, I introduced it to a few parents and a few young people, but it's kids with autism that have little or no language. Um, one boy was at _____ in Washington D.C., and his teacher worked at _____ with my son, and I knew his mother, so I tried facilitating with him. It takes , it really takes a relationship with someone, and R knew us, we'd been in a research project, um, so I was able to facilitate with him. And then there's a young girl at _____ who was in the same project, and I was friends with her and her parents and she was very comfortable with me, so I facilitated with her, um, and just several other young people just demonstrating, but not on a regular basis, as I do with my son.

9. Well, I took the very first training that they ever had in Syracuse, and um, I believe it was October of 1990, and it took about a month to work up the nerve to try it with my son, at the time I was the only person in _____ who

had tried it or was working with it, and, um, so I didn't have any support. I didn't have anyone to call other than the people I had met in Syracuse. Um, that I was friends with, and they kind of helped me through it. But it was not successful from the start, with M, it took, all I was getting from him were yes and no, and a few kind of gibberish answers, every once in a while something would come out that made sense, but, um, I kept telling everyone I know he can do this, but this is something he thinks I'm just doing with him, it's another thing mom's making me do. So I worked with him for a good, almost 13 months. And he went to _____ Camp, can I go ahead and tell this? Okay, he went to _____ Camp, and this teacher I was telling you about from _____ was volunteering that weekend, and so she facilitated with him, Because they told her his mom said he's been facilitating at home, but he had never gotten to a sentence level with me, nothing over just filling in a few sentences or filling in the blank, not even finishing words. Um, he told them jokes, he teased, he said that he wanted to tease two of the counselors, and he, they had been to a tanning salon, so he asked them where they had bought their suntans, and they thought that was really funny. Um, he wanted to tell them jokes and all, and told them a beautiful Christmas story, because it was in December, and for their talent night he made one up. And they were saying how beautiful it was, and he said, "Don't tell my mom. Don't let my mom know I did this," and they said "Oh, M why not?" and he said, he was spelling, he said, "She will be mad because I don't do it at home and I don't do it at school." And they finally convinced him after working on him all weekend, "Oh no, we have to tell your mother. We've got to share the story you've written." So he said, "Alright, you can if you have to." and when he came home from camp, another mom picked him up, she said he was standing taller, he was prouder, she said there was a real change in his body posture. He came home with the letter, my husband read it, got tears in his eyes, he was so excited, and I got mad. I was so mad at him, because I'd been working with him everyday, and I said, you little rat, I love you more than anyone else, and but, one of the things I had learned from Syracuse, but it was hard to keep in my head because I'd also had some training at the TASH Conference, the Association for the Severely Handicapped, in Washington DC, and I kept asking people was I think my son has this potential but he's not doing it, and they said remember, that your relationship with him as a parent is totally different than a relationship with other people. It's kind of hard for a teenager to talk about...so I was mad at him after I found out, for about two or three days and it took me a long time, I had to kind of work through my feelings, and finally I told him that I was really sorry and I apologized that I was mad at him for using the facilitation with other people. Because he hadn't done it with me, and I was sorry I had let my feelings get in the way, but the main thing was he had someone with whom he could talk and communicate with, and that although K lived in _____ that we would figure out a way to at least once a month if not more often to go up there and see her so that he could have someone he could talk with, and after I said that he just started spelling and said, "Okay Mom, I knew you were going to be mad," and he said, "I hurt, you need to take me to the doctor, both of my ears are infected," and I took him to the doctor and both of his ears were infected. And that's when it started. But, do you have this in a question later? There are times when M doesn't facilitate at all. Okay, he stopped, well, the summer after he started facilitating in that December with me, he stopped facilitating for three months in that summer. Um, I had been so excited about him facilitating, that when we'd go into the grocery store I'd get him to spell "Hi" to people, and he just got tired of being on display, and also, as a teenager, he has his own agenda, and he really wants his voice to work, and he stopped spelling totally for three months, and I just kept giving him opportunities, but I didn't push it, because I had talked to some people in Syracuse, and they said that happens. Sometimes they put a lot of pressure on themselves, or, I guess I was putting a lot of pressure on him. Same thing happened with us at school. It was written in his IEP, his teacher was trying everything to get him to facilitate everyday. I would say, "Why aren't you facilitating at school?" And he would say, "I don't know. Try telling the teacher to take me to the bathroom, try telling the teacher to hold my hand." And I kept saying, "You have to facilitate because they have to know how smart you are." Finally one day in February, after the school year had started in September, I said to him, "I don't care whether you facilitate." Oh, and another thing, when he was in the seventh grade and wouldn't facilitate, I said, "If you can't facilitate with your speech therapist, I'm coming to school, and I'll walk around with you, and I'll take classes with you. Which is the last thing a seventh grader, who's thirteen years old, wants to hear. Finally, I just said, I don't care. I don't care if they know what level you are, obviously you've picked it up on your own, well just get books for you at home and let you just keep self-educating yourself. I don't care what you do at school anymore, you know. And, I told him that probably one weekend, and by that Wednesday, he facilitated. The same day with his teacher, his aide, and his speech therapist. And I asked him why, and he said, "I don't know, I just could." I think it was because the pressure was off of him, and he knew it didn't really matter. And I didn't realize I was putting that much pressure on him, but looking back, I was really pressuring him on it, to facilitate, and he can still, there are some days when it is very difficult on him physically to facilitate. Some days he has more tremor than others, and some days he's just too tired, so, some days he's more in control of his body than others, and if he doesn't want to, that's fine.

10. Prior to being trained? No, not really, other than a real feel for people with autism and communication problems. And a real frustration with sometimes M asking for something, repeatedy asking for something, and

then when you'd give it to him, hed just get mad and throw it at you, or something. Or, you know, he'd ask for chicken noodle soup, chicken noodle soup, chicken noodle soup, and you'd fix him chicken noodle soup, and he'd pour it down the sink. Or, french fries, french fries, french fries, and you'd buy him french fries, and he'd throw 'em, and when he started facilitating, he would say he was saying the closest thing that he could say to what he really wanted. So an idea that a lot, I just had an idea that a lot of things that his voice was saying really weren't what he meant, because the frustration level was on both of his eyes. Um, no, because there weren't any out. Um, we, well, by the time we started, um, J had been doing it for a year. They started in '89, and I had talked to [his parents] and um, known a little bit about what J was doing. It was very interesting, J had no voice at all. Um, so, I thought J's problem was a pure autism and a speech, getting it out, and I thought M had more mental retardation, so I thought it was probably a more viable method for J, that because M could talk, he was probably more mentally retarded, and it wouldn't work for him. A friend of mine who's a teacher said, "Let me get this straight, you thought he was more mentally retarded because he could speak?" And I said, "Yeah." Yeah, I thought M's was a more physical block, and I thought M's wasn't because he could get words out.

11. Oh, golly, as I was telling you, I went through a lot of training, and for the first 13 months I was doing it with M I don't think I had enough training. I went to the first four day workshop that they had up in Syracuse. Um, but I didn't really have anybody helping me, so I really wasn't doing it as well, obviously, because M had a hard time working with me, and um, um, so I had an initial training at a conference in Syracuse then I went to an all day training in _____. First in the fall, then in the spring, I took a one day workshop where I got some more information, then, then, um, I went back to Syracuse every year for the conferences. This year, this past year was the first year I hadn't been, but I went to trainings, lots of introductory workshops, and I went to a training, in, at TASH, they had a two day workshop at TASH, where I had additional training, and that was really, let's see, I had the Syracuse training, the one day at _____, and the training at TASH all before M started being fluent in it, so, um, it just took, I guess what it really took for me was to get really relaxed, and to realize that my son's whole life didn't depend on it. I think I was so nervous about it, that since I used facilitation, and started the training and tried to train other people, it's really amazing what your touch can convey, and if you're tense and you're nervous, um, particularly for someone with as much anxiety as my son has, it translates through touch. And I think when I finally just, the day I said I don't care whether you do it with me anymore, I'll just, you know I'll make sure you get to K, obviously I'm not very good at it, when I finally just came to that, letting go, kind of, of, my own, and worrying, I guess there was a lot of worry, when I finally just did that, then

M could facilitate with me. And I also learned over that course of three months during the summer when he wouldn't facilitate with me, not to think of it as such a big deal. So, but you need a lot of training.

12. Um, I think that the initial training that I got, everybody was just learning about facilitated communication, and that's why it's really important to keep up with what they're learning as it's going on, and I think they initially made some statements that they've had to change their minds about. I think that as a parent it was harder for me to pick up on some of the things that a professional in the field could. I mean, I had so much emotion invested in it, that I think it was harder for me. So I guess I would have to say, my first couple of trainings were just on the physical aspects of it, and not, I guess a little on the emotional aspects of it, but it was so new, I think I had to experience some of what was going on before I understood what they were really trying to tell us in the training, um, that's why I think if you had, I think what would have really helped me after the initial training, it would have been sufficient had I had a support group and a network around me that I could problem solve, and talk about things with, also, I was the only one trying to facilitate with my son, and we can get to this later, but I think one of the best practices that you can do is train a lot of facilitators. Okay, one of the things is, I think it's really important to train several people around one individual, so that you can network with each other. You might try, one person might say, "Oh, I found that if you hold his hand or pull back a certain number of inches it works better and, um, if you're all experiencing frustration then you can kind of talk to each other about it, but it's really good to brainstorm and have a whole group of people, and it's also more supportive for the person that's being facilitated, so that they don't depend on one person so much. And what you want to work to is independence.

13. Pretty much people with autism, although there is one young man with, uh CP, that I've used it with.

14. Um, well certainly people with autism, and people with CP, it helps to provide a staying touch for someone that has a tremor, I think that they have used it successfully although I have not tried it, with some people with Down Syndrome, who have some speech, quality of speech that's hard to understand. I think it would be kind of neat to try it with people who have had strokes. Um, certainly choices, and um, one of the things that we learned with M, um, and other people with autism, it doesn't look like a body movement disorder, but it is. A lot of times, uh, people will be doing something, and they'll freeze, or they'll stop completely, M does this quite frequently when he's walking along. And one thing that we've learned through our training with facilitated communication is, if you just give him a touch on the shoulder, sometimes a physical prompt allows him

to start walking again and doing things independently even if you've never used the spelling techniques with people if you start looking at the way they're having body movement problems, I've found that we can help that population. I've been reading a lot of Oliver Sack's books, and um, it seems like a lot of people with neurological problems that he's dealt with, if you read Awakenings, I don't know if you've seen the movie, if you remember there were certain times in the movie when people could do things, if you played a certain type of music for them, they could eat, if you threw them a ball, they could catch it, but they couldn't take it and throw it to start off with. Um, a lot of time, I think they'd touch the people and then they could throw the ball. Um, I think sometimes the focus on facilitated communication has been a lot on the spelling and un, uh, unrecognized intellectual capacity of people, because as a society we certainly judge people on the way that they speak, and they make lots of jokes on southern accents, or mountain accents, or, a lot of blacks have been judged on um, that are street smart don't do well on tests that are vocabulary based, or, um so this country has a tendency to do that. But, what I think you should look at with facilitated communication, is maybe not so much the spelling, but maybe the movement disorder, and if you read Anne Donnellan and Martha Leary's book, they talk about that a lot, and that's been really exciting for me, because um, we realized a lot of things Matthew does are accommodations for the way he has to move.

15. Well, I though it worked for Jeffrey, I didn't think it would work for M. Because I told you, I kind of thought it would work for a lot of other people because they weren't verbal, but I didn't think it would work for my son, because he was verbal, so I guess those were the beliefs that I held. Um, there was one book that was written for parents, um, its called If You Look Into Their Eyes You Know. I think that a lot of us parents who have children with special needs have known for a long time there's a lot in there, than we're able to, than they're able to get out, or that other people are able to elicit, so I guess I thought, well, this is just a new technology, that um, is enabling us to be able to reach people better. Um, I have, um, been to some trainings, by um, Dr. _____ at _____ college going off the work of Dr. Feuerstein in Israel, who um, teaches something called cognitive modifiability. I don't know if you've heard anything about that. Um, he talked a long time ago about people with um, autism. Okay, I was talking about Dr. Reuben Feurstein's work. Um, he teaches something called cognitive modifiability, where he was saying people with autism and people with Down Syndrome and people with some other severe and profound handicaps, um, have the ability to do more if they're given the technology of working with a computer. And, um, somebody very supportive. So, when I first heard of facilitated communication, I told Doug Biklen, who is one of the first researchers, about Dr. Feurstein. He didn't really think there was a parallel, but I do. Um, I guess I was enthusiastic, but, I guess with your own kid, the grass is always browner, so I wasn't

sure it was gonna work with M or some of the people I knew, but it was still kind of an exciting avenue. Um, I do believe that people can influence and certainly M has had probably 50-55 different facilitators, he transfers very easily to other people. But I would be very naive if I thought somewhere along the way someone had not moved his hand. Because I think if you haven't had the proper training and experience, it's very easy to get real enthusiastic and kind of anticipate what you think someone's going to say and kind of subconsciously move it.

16. Um, well as a parent, it was pretty traumatic, I mean in a way it makes me angry when people say parents are so desperate and are willing to believe anything, and you know, they'll believe that their kids are spelling. Because I know that's one of the arguments against it. Um, but it wasn't easy for me. When M first started using facilitated communication, it was, I had to come to grips with his disability all over again, and um, a lot of the emotional things I had been through, I had to, I just experienced all over again. And, in a way it made it harder on him and harder on me, um, after I found out that he understood more than I realized he did, then I started not forgiving some of the things that I understood were part of his disability. I remember one really good example of that was when he threw a tantrum in the doctor's office, um, in the pediatrician's office, because he wanted to be seen in the back, and normally whenever he goes to a doctor's office, if they have any experience with M, they hustle him back to an examining room right away, they don't leave him in the waiting room because he can't handle it very well and he threw a big tantrum. And when we went back into the examining room, I was upset with him for throwing the tantrum, and I said, "Why did you do that?" and he said, "Because I didn't want to wait. I shouldn't have to wait." And I said, "All the other kids out there are sick too." And he said, "Yes, but I'm more important." And I was so angry that I think when the doctor came in steam was coming out of my ears. Um, he said, "Well, aren't you glad that he could tell you that?" And I said, "No, I'm not so sure I'm glad he told me that. Because all this time I thought he couldn't wait because he didn't understand waiting, not that he couldn't wait because he thought he was more important than everyone else." But, um, M has two doctors, a pediatrician and a psychiatrist who help me kind of go through what M is saying, and the psychiatrist explained to me that was adolescence, not autism, and they're very extremely self focused in adolescence, but another thing that's been very difficult, well M said some things to me and to his grandmother that were very dirty. Um, very shocking to hear from your grandson, and the psychiatrist pointed out to us again that that was part of adolescent testing, he didn't have any guys in the locker room to test things out on, so you know, unfortunately it just kind of happened, and for us to keep that in perspective. Which we had to. And then, it's been really difficult. I thought that M really wasn't aware as much as he is of the

differences, and he said things to me like hurting in my heart because I'm not like the other kids, hurting in my heart because (well, he doesn't use people first language) he says because I'm autistic and I'm handicapped. I say, you're a person with autism, but he has his own terminology. It's been kind of difficult to hear him say things like that, and um, I always thought he wasn't aware of other people and friends and um, I really didn't think that it made much of a difference to him. So that's been really difficult. I don't know if I'm really answering that question or not. How have my beliefs changed? Um, I guess the other thing that's happened is I think I see more possibilities for people if they get proper positioning. Not just in communication, but in doing other things independently. I think that, uh, that's something they haven't looked at with people that use wheelchairs. Or that are more physically involved than they have looked at people who have more mobility. People with Down Syndrome or autism may have more positioning problems than realized. That's one thing that I've started looking into.

17. Well, yeah. M said some things to me that were quite surprising. Um, a lot of them I didn't want to hear. And that's something you go through whether or not a child has freedom, you don't want to take away somebody's freedom of speech or communication, but at the same time you don't feel like your child should be using four letter words with you. So finally I just decided I'm gonna be a parent and not a facilitator and, you know, if you're gonna talk like that, I'm not gonna talk with you, you know? That's been a struggle. Trying to figure out what to do, um, but one thing that was surprising one time was actually I was facilitating and he and his brother were in a big argument, and I just kind of let, I was the facilitator, and I was reading back to his younger brother what he was saying. But it was kind of a funny, it was a surprising situation to be in. And Trevor was calling, T's my younger son, he was calling M an idiot, and M was saying, "T, you're a brat," he was spelling it and I was saying that to T, and T was yelling directly back at M, and I was the one using M, reading what M was saying, but it was really kind of interesting. You know, T certainly accepted the fact that it wasn't coming from me, it was coming from his brother. Um, that was interesting. And some of the things that have surprised all of us, um, a lot of times things would be lost in the house and find out, M would spell where they were. I found out that he doesn't always tell the truth, too. Um, he did tell me one time when he was at day camp that he was having a problem with some boys teasing him. And he gave me all the names of the boys, and I told his camp counselor. There weren't any kids with that name. But the camp counselor went ahead and investigated it, and it was true, some kids were giving him a hard time. And I asked him later why, if he didn't know the right names, why he made up names, and he said because I thought you wouldn't believe me unless I made up names, or you know, unless I gave you some names. And I said,

but they were the wrong names, M. And it's been interesting to find out that there is a part of his disability that's been listed as a characteristic, that he doesn't have some of that social reciprocity, and, um, empathy, and it was surprising to me that he would say to people, it was nice to meet you, and spell that, and have some of those social things, but also at the same time to find out that he pulled people's hair because he thought it was funny. And he had no idea that it was hurting other people. And, he was saying he was doing things because he thought they were funny, which were not funny, they were only funny to M, and we had to teach him, I mean, he said, teach me what's funny, and we've had to teach him it's only funny if more than one person is laughing. Um, so that was something that we really learned different.

18. Well, we've been keeping kind of a validation notebook on M. For instance, uh, there've been times when he's talked about something at school that happened at home, and, or something and people, at Thanksgiving one year, we told a famous story about his uncle, when he was a boy, jumping out of a tree using a sheet for a parachute, and M went to school the next week telling his teacher about his uncle falling out of the tree, and she was very upset. You, know, there was no way she'd have known about it, and she wrote home and said, "Oh I'm so worried about M's uncle falling out of the tree," and we had to write back and explain, um, that was just a story that he was trying to tell you. But he couldn't get out completely what it was, and he couldn't tell her that it was just a family story. So that's one of the ways that we've validated, and...he played a joke on his brother, and told his brother that he'd flushed a hermit crab down the toilet because it looked like it was thirsty. His brother was very upset and crying, and he was, this was when he was about 13, he was snickering. And finally he told me, give me more credit than that, Mom, he's under the bed. And we went upstairs and looked, and sure enough, that's where the hermit crab was. We had no idea where the hermit crab was, he was missing. Um, so those are some of the validations. Um, there have been times when he has gotten stuck, and he's repeated some of the same words over and over again, and hasn't been able to get out what I think he's wanted to say. I don't know if you have this in any of your other questions, but I think one of the things that's important when you're learning facilitation but also to people being facilitated, they need to learn that they need to let you know that you might be leading them, or that you might be influencing them, or just by the questions you ask, or by the way you answer some of them. You might be misinterpreting, and you might, before they finish a statement, ask another question and make them get off on a different track. So one of the things that I think is real important, is a best practice is to teach the speaker who is being facilitated to hit a block, or to say no or some way to indicate that you might be either

misinterpreting or leading them, influencing them, what they have to say. So, I think that's a real important skill to teach the speaker.

19. Any modifications, um, I think it's important for people to get proper training and to understand and to understand that they can lead and they can interpret. I think it's very important to keep working towards independence, that's what we're doing with M, and then to realize it's emotional and also physical, and um, there've been times when he's typed on his own. Uh, (Interviewer-Without any physical support?) yes, not very much, um, there have been some times with me when I've just put my finger on his elbow and he's been able to type, but, it's been, it was extremely emotional for him, so I think it's something that you have to talk together with him, but, uh, to realize that not everyone will have that much physical control, and that there are days, I think there are lots of days, when M needs more physical assistance than other days, but we keep trying to move the support back, so that the goal for M is to work towards independence. I am extremely frustrated with the school system, because although that's an IEP goal, for him to work towards independence, um, they really haven't had any training for the people who are trying to facilitate with him at school. So how can you work towards independence, if you don't have a good background, or the physiology and why you're doing it, and how you would back, back off. (Interviewer-So you think they need more of an understanding of the kinds of students their working with, or more of an understanding of their disability and what they can and can't do?) Yeah, or just kind of more of a body movement understanding. I think that with M has very echolalic behavior, he has very perseverative behavior I think the reason facilitated communication has worked for him is that it's been able to stop a perseveration on a typewriter key. I think with other students it might be something else, you know a hand positioning kind of thing, or with, as I was saying before, with CP people you can get the right angle on the board and the right angle in the chair, they're able to do more things independently. I think that teachers and speech therapists should get some training in that. And an idea behind why the person is using facilitated communication um, and so that you can have the relationship, or trust, so that the person can know we're working towards independence, but if it's too much for you today, we're not going to push it and you know, um, I don't know how else to explain it. But, I think it's real important for people using facilitated communication who are the facilitators to be aware they can influence people and for best practices you need to videotape yourself while you're doing facilitated communication, you need to have somebody else who's trained in facilitation to observe you, um, I think you need to always be aware that you can influence people. With my son, when I think I know what's coming up next, when I think I know what he's going to spell I make sure that I always bring his hand back to a neutral position, and I kind of probably

give him a little bit more backwards resistance, when I think I know what's coming next, so that I make sure I'm not going to be influencing his next letter choice.

20. Well, sure, but we're still continuing with M with speech therapy. It's a good method of communication for him, and it's opened up a lot of doors, but it's still not, it'll never equal speech. The rate is so much slower than speech. I mean, it's, when you really get going, you can talk three hundred words a minute, or more, sometimes I think I'm about five or six hundred words, um, and even the best typist is what, 140? I don't really know, but, and then when you think about somebody only using one finger and then somebody else pulling back that finger and supporting, I think that it's very, it's not very effective, and what we've been trying to use with M are phrase books and quick books, where the phrase is already written out and he can point to it, but he doesn't really like those. I've been trying to teach him that he can answer in slang or answer quickly, if you ask him a question, he usually goes through this whole thing of, "Did you have a good time at school today?" "Yes, I had a good time at school today." Where he could have just said yeah, and typed out yeah, but he's very formal and stylized.

21. You mean at what age, or (Interviewer- Um, I guess at what, um, if you have a certain child, and you want to use facilitated communication with that child or person, adult, when do you think would be a very good time to use it with that person, not necessarily the age level, but, um, how would you determine whether or not you should use it with that person?) Well, if it would enhance communication, I think you should at least you know, give it a try, preschoolers, before they really have language, you can do choices, you know, red, well remembering that some people are red/green color blind, but you can help them point to choices, um, I think that they should try it with people who have had strokes, and you know, uh, and if you don't want to use a spelling chart, you can use it for pictures, you know, anything that increases independence. I think that you have to think about people with disabilities, you want to do something that does the least harm. Go on the assumption that it does the least harm, and if someone has a severe communication deficit, um, I think it would do more harm not to give them an option for communication. Um, I still think it's important that, that the facilitator is somebody that has experience and it's not somebody that...it's very, very difficult to understand it and to get it from just routine work or watching a TV program. You just can't do it that way, and in fact in Syracuse, they haven't come up with a certification, for people but the very least recommendations that we could come up with are you need to be trained by someone who's actually used it and done it, and actually used it with a speaker and not just trained another professional, or another professional has shown, because it's quite different with a

speaker. And one thing I've found with the different individuals, is, you use a different touch with some people, um the kid I was telling you about in Washington DC um, has very soft flaccid hands, and we just would hold his hand he would just barely point, and depending on my son's emotional state, he bangs down, and you have to just really pull back really hard, um sometimes with him. Sometimes he's in a very relaxed state, and you can kind of just back off with him and kind of just give him a little support, and I think its really important to learn that even within individuals, you would vary the amount of support. And one thing, as I was telling you before, that I learned when I was training other people, is so much is communicated through touch. I think that's why some people are more, um, natural facilitators than others and I think that's something that, in training, people.. needs to be reflected. And I think that's why sometimes in some school systems, some people can do it better than some other people, um it's just surprising, when you're really nervous, and I was trying to learn something new, if you're trying to, when I was trying to learn how to roller blade, I was trying to do it on my own, I kept falling down, um, when my youngest son was trying to help me, he was pushing me around, it didn't give me any confidence at all, when my husband just gave me a steady, warm hand that was very confident he didn't even have to say anything, just, I was able to do more. I think that's what I'm kind of trying to say.

22. No, I just think that, well I think that that Frontline program um, on PBS that talked about prisoners of silence and people in the state institution in New York who were facilitating, and then they did the test on them and all the tests results said they, it was all facilitator influence, um, I think that...I have done a videotape myself on one of the projects I worked on, and it's quite easy to take one editorial point of view and push it. It's very easy to take clips and support your own point of view. I think it's been, um, very unfortunate that people have looked at only quantitative studies and not qualitative studies looking at facilitated communication. I think that, there's a study that Don Cardinal has done in California where he used 43 individuals, the biggest qualitative study that proved that facilitated communication worked, has not gotten the press that the negative studies have. I think that when you study it, you have to look at the editorial boards of the professional journals, um, Dr. Schopler of Division TEACH is one of the biggest critics of facilitated communication, and he's built a whole career out of what people with autism can't do, and this kind of flies in the face of it. He sits on the board, the review boards of the magazines that would publish favorable studies. Not to single out Dr. Shopler, but I think there's a lot of politics that play into what gets published, that, um, I found out there was one study done that, the designs were not making accommodations for the people who had the disability, people were failing facilitated communication tests because they couldn't get the correct

answer within ten minutes which was a study time constraint, but at twenty minutes, and thirty minutes they gave the right answer, and if you're gonna use facilitated communication with somebody, you need to have enough time to sit there, as I said, it's not really effective, it's effective, but it's not really efficient, so I think that when you are making, I think that a lot of the people who are doing some of the studies are people with psychology backgrounds that don't have a feel for the disability itself, but it's kind of a quick and easy way to get the study done. You need to make an accommodation for the disability itself, and you need to understand before you design a study, that people, you can't use those kinds of time constraints, or how can you throw out an answer as invalid if it's the one you want, but it came ten minutes later? I still think it's very good. I think that there are people that, with all the best intentions in the world, say what they think the person wants to say and move their hand around. So I think its important to acknowledge that. I do think that it's easy to misinterpret what someone is saying and I can give you an example of that with my own son, he told me um, we visited a family, and he put his head through their front window. We were visiting, and we had to go to the hospital and get him stitched up, and he said, it was my friend J's house and we were coming back in the car, and he said, "Tell J I'm going to kill myself." And when you see that typed out, you just kind of go... and I thought, Oh my goodness, you know, he's, he's having suicidal thoughts because he broke her window, and all, and I was very upset and very nervous, and I said, well, why would you say that? and he said, "Because I'm so clumsy, I was rocking too far." He rocked, you know, just doing one of his body motions, he rocked through the window and he meant kill myself the way, the slangy way we say, oh I, his brother said, "I fell off my bike and I nearly killed myself." Um, when you see it in print without the facial expression it's very easy to misinterpret. But, um, it's just a cautionary thing.

Subject #2

1. I'm a speech language pathologist. I have a Master's degree. I got my undergraduate degree at _____ and my Master's degree at _____

2. No, I don't.

3. Yes, it is. I, um, in this job that I'm sitting at right now, I'm the director of a non-profit foundation. The mission of this foundation is to support and help families who have children with developmental disabilities. We started off ten years ago just working with families who had children with autism. We have since taken on, um, working with all types of developmental disabilities.

4. Classes in school? Well, darling, it's been a long time since I've been in school. Um, so, uh, I'm not really doing speech pathology right now, but I would say that most of the work in communication that I did in graduate school led not, led me to really the, the deep belief that I have that people with autism and developmental disabilities have a language disability, um, that that is one of their most severe deficits. How I come at treatment almost always incorporates language or communication. In addition I took a lot of psychology classes, and those gave me the understanding of development and uh, it helped, and I also learned in graduate school about behavior management charting, and counting behaviors and how to, to analyze behaviors. So that's what I use from school at this point. I graduated from my master's in 1973 so I just look young.

5. Um, I, I've always been, um, open to people who are different. Uh, I grew up in a town called _____. You may have heard of the _____ Social Maturity Scale. That's where that scale was developed and normed and the reason that scale was developed there is because there is a huge institution there and as a child, my whole family was involved with things that went on there, so my father owned a retail business and we had people all the time coming in to our store who had disabilities so I was never afraid or uncomfortable around people with disabilities and I just have that social services blood in me. I originally wanted to be a physical therapist. I looked at the curriculum, I thought, 'There's no way I'm going to do all this science.' So, um, I took speech pathology and I just, I feel very comfortable with people who have disabilities.

6. Um, a little bit with physical disabilities, not a lot, but um mostly with autism, mental retardation, second, 'course kids with speech language problems. I came out of my Master's degree and started working right away in a school that had kids with autism, it was just a real interest of

mine in graduate school and I've been doing it ever since. There's always kids with, you know, cerebral palsy, and Down's and you know, thrown in, but my main focus has been PDD autism.

7. Not on a regular basis. I have a friend, with whom I facilitate when I get together with him. He's a young man who I met about fifteen years ago. He's 25 now, and at the time I met him, he was in a residential school where I was working, which is at _____. And he lives in _____ now in a group home, so I, and I facilitated with him a lot um, when I first learned about facilitating, and when I'm with him, I always have chart. If we go out to eat, we go to a baseball game, you know, I always take a chart, because he's verbal, but his verbal is, um, very echolalic. So I think this is more accurate, facilitation.

8. Absolutely, I'm a speech therapist. Yes, signing, picture flip books, and picture charts, and uh, uh, cued speech, um typing, you know typing without facilitation, pointing without facilitation, uh, not photographs but symbols. They're called bliss? symbols. We've done it all. Mostly again, with autism and mental retardation.

9. I guess it was five years ago. How long ago did B say that she had? Cause she was the one who told me about it at first. Her son was in one of our programs. We had a Saturday recreation program. He was, oh, gosh, he was so young then. And she started bringing in these little typed things from him and it would be like garbage, garbage, garbage, you know, letters, letters, letters, and then there'd be a word in there and she'd be showing them to me, and I'd be like, "What is this? What are you showing me?" And she, week after week she'd bring them to this recreation program and show me these little strips and then finally, you know, she started bringing me articles, and then as soon as I could get to Syracuse, I went. So probably1990 was when I went to training. She went to the, the training, the actual formal training, you know, a couple months before I did.

10. Uh, I started reading as soon as I, you know, found out about it, and felt that there was some validity to it, and that it was something that may help some kids, which is always my interest. Not that it's going to help everyone, it may help some kids. I started combing for articles and as soon as you start talking about it, information comes. That's just the way it is. So I had read some before I went to Syracuse. Not an enormous amount. But in 1990, there wasn't an enormous amount.

11. Um, I went to Syracuse and I took a three day training course there. It was intensive, three full days. You know, it'd start off early in the morning, go until 5 or 6, and then people stayed around and practiced, and talked and shared information. Um, so that's what I did initially, and um, since then, I

have taken several one or two day local workshops in order to learn how to not influence, you know, in order to be updated on the research.

12. Yes, I think that what I learned initially gave me what I needed to get started. What is the weak link for me about the training is that I, the whole group that I got trained with were people from all over the United States, then we all came back to our communities and we didn't really have a support system here. We still don't really have a support system, so it's hard to um, sustain it. Um, it would be kind of like trying to be a recovering alcoholic without having AA to go to. You need that constant, especially with something like this.

13. Um, I have used this with some individuals who have cerebral palsy, uh, individuals who are mentally retarded, people who have oral dyspraxia, or oral dysphasia who can speak but can't really get it out when they want to get it out. I've always been interested in, but haven't had the opportunity to use it with people who have had strokes. I think in a way it might be interesting, because this is a different, um, connection to the brain than this is. Um, and of course with people with autism. I say autism, but it's always autism, pervasive developmental disorders lumped into one.

14. All of the ones I just mentioned. I think there are individuals in all those populations that I have seen successful.

15. Um, no I don't think so. There was nothing that was prejudicing me. I was excited about it, and I just allowed the door to be opened.

16. Uh, well, my, my belief in the technique has been strengthened. When I had the training I have to say, you know, truthfully I walked away going, "You know, I just don't know about this. I just don't really know." But I was actually doing speech therapy at that time with five individuals in a group home, and three of them had autism and had severe communication problems. So I came back and I started videotaping them and I started facilitating with them, um, you know, nothing, day after day, nothing, day after day. And then I had one of those times when I had an individual spell out something completely different than what was in my head, what I was predicting the answer to be. You know, what kind of a day is it today, and it was cold, and gray, and I would have written those words, you know, and uh, he kept going towards certain letters, and he kept going, and it was you know, like this chart and he was going down here, and I would pull him back, because that wasn't anywhere near the 'C' for 'cold', you know. When I just released myself and let him do it, he spelled out foggy and at that moment, I just got goosebumps, and I thought 'Wow, he can spell foggy.' You know, 'He's really doing this, it's not me,' you know, and it, it really frightened me to be more open, but I have to say that, you know, all

of the horror stories that get publicized, you know sensationally on the T.V. and even in the literature have not made me skeptical, but have made me cautious.

17. Well, that certainly has been a surprise. There have been times when you know kids who, um, I would go to see for the first time. I would get called in to do an initial evaluation. You know, we've heard about facilitated communication, we have this kid, and we think he understands everything and we want to see would he be a good candidate. And you know, it's in a sheltered workshop, and there are 55 severely mentally retarded people sitting around packing forks, knives, and spoons, and um, and I've just been shocked at the intelligence level of individuals who have no way to communicate verbally, through typing, or through writing, and then you give them that support, and I think it's not just the physical support, I think it's the emotional, the personal support. All of that together is what makes it work, and having them spell out things that I have no knowledge of because these are people that I have just come into contact with for the first time. So, you know, those kinds of things have been just been so exciting. Very exciting for me. And for the people that work with him, you know, families and everything.

    Did you call the couple, Mr. and Mrs. D? Oh, their daughter, oh, my daughter's a sophomore in college, but four years ago, when she was a junior in high school, their daughter came into her high school. She had been in a special ed school for her whole life and well, he'll tell you the story, it's just an incredible story. And my daughter has the same blood in her that I have and she wants to be a special ed teacher. And she's just getting into her education classes. You know, her sophomore year, she's taking, what is she taking? She's taking developmental, and you know, anyway, she started facilitating with N and N had a facilitator with her all the time. That would be a good person too, but I don't know that person. Mr. D. could turn you on to her, who was N's facilitator. Um, that, that child, who's now 20. She has an intelligence level just as you and I do, she just had no way to ever communicate with anybody. And, um, it, it was so neat to see these teenagers when they'd get together, because N would go to the football games with the kids who were accustomed and "Hey," you know, "you want to go get something to drink?" and she would point to yes or no and "What do you want?" and she would type it out and she's amazing to watch. So I hope you get the opportunity to see some people facilitating. It's eerie. It really is.

18. Absolutely. Much more than verbal. Because one of the kids that I facilitate with is echolalic. And it may be really delayed echolalia. You know, where he's heard people say certain things, and it just kind of pills out the way it does with people who have Tourette's, or people who have

had strokes. And, um, let me give you a brochure before you leave. We're having a conference, and a woman who's coming to speak at out conference has a theory that it's a movement disorder as much as a cognitive disorder. You know, when these words come out, and it's sort of like a tic. It just pops out the way burps do. So I would say to him 'Let's go get something to eat. What do you want to get?' and he would say 'McDonald's is your kind of place.' And I would say, 'Oh, you want to go to McDonald's.' 'Yeah, McDonald's. Yeah, McDonald's.' And then we'd get there, that's not what he wanted at all. You know, he really wanted to go to Sizzler, or, you know, something else. So if we use this, or even in facilitation I would go through the phone book with him you know, through the yellow pages, and I'd say 'Here's this, here's this, here's this' where he could read it, and so many of these people can read. And I have asked this one kid in particular, 'I mean, how did you learn how to read? How did you learn?' And he said, road signs, magazines, T.V. I mean, think how smart he is. He learned how to read without formal reading instruction. So, yes, I believe it. I believe it's a very valid form of, accurate form of, communication for some individuals.

19. Well, B and I both worked on this facilitated communication task force which I mean for weeks and weeks and weeks. You know what a task force is. The governor says somebody has requested funds for something, let's have a task force study it, or you know, they want to change regulations, uh, curriculum across the state, so you have to do a study group of it. And, um, there needs to be some more kind of organized training, preparation, for teachers and aides, and, well, professionals and paraprofessionals who work with individuals with developmental disabilities, so that when someone comes into their school and into their class that they don't have to right then learn it on the spot. We were proposing like a resource center. Some kind of clearinghouse where you know, somebody from _____ would need some technical assistance, there would be funds, and there would be professionals, you know, that could be sent out right away. If it's overregulated, then that would mean that someone like you who goes to volunteer, you know, like one weekend a month at a center where there are kids and there are kids using facilitated communication, that you'd have to go through some humongous training before you could facilitate and that would make it difficult for people to communicate with many varied individuals which is of course what we want. We want kids to be able to communicate with the kids in their classes, and not necessarily have an adult around all the time. Because if there's an adult, then they're not going to say, 'God, I hate that teacher' you know, so, but yes training is a very big problem, and I think that if we had some, uh, validity studies that weren't biased.

20. Um, hm, yeah. I'm happy to use it. We do, um different training here. We do not do facilitated communication training, but we do other types of training, and we always carry a chart around. And when non-verbal kids come in, I always talk to parents about have you tried it, are you interested in it. And if they are, I'll start giving them the information and I'll even facilitate with kids. This is a doctor's office also. The front of the Building is a pediatric neurologist and he will have me come in with a client, um, and do an FC evaluation to see if this is an individual who might benefit from that, and then the parents can go back to their school or back to their whatever and make, you know, make the pitch for it themselves. Um, but we give them the information and I say 'Look, he just spelled out pizza' and you know, 'Screw off' you know, whatever.

21. Um, well, I'll tell ya, as a speech pathologist, it was really hard for me to swallow in the beginning because we always want to try to get people to talk, but, um, I feel like one of the best things that we can do for an individual if they do not have a, if they do not have a functional communication system is to give them one, early. And whether it's FC, or pointing, or, you know, signing, whatever, to give them a functional system. Why I say all that is because when children are about two and they haven't started talking yet, it's time for them to get an alternative system. I would try FC. You know, even if they're not using a spelling chart, if they have a picture chart, but are supported with the pointing, which is the way a lot of little kids get started, you know when I'm doing an evaluation, I just use pictures to start. If they can do pictures, then we go to letters. I don't see any reason why children can't be screened if, you know, when they're going to preschool special ed classes and that's at age three, that they can't be screened to see if this would be a way to help them. You know, a lot of kids need to see that communication works. You know, that's why sometimes you start kids with a couple signs. A couple little signs, and then they start communicating verbally. They didn't understand. What was communication all about? That you go like this, and you get more. That you go like this, and you get a drink. So it could get them over the hump. It could be like a bridge to communication. Or it could be a way for them to tell us what they really want so they don't have to throw a tantrum. Um, well, I think people who are very severely physically disabled, it would be a difficult process. I have seen tapes of Rosemary Crossley using it with really severe people with cerebral palsy. I'm not sure if I feel comfortable doing that. People who are mildly, have mild muscular, um, physical difficulties, I think, and they're involved motorically with the speech mechanism, I think it's great. I definitely, definitely, think it's the root to go with kids with autism. I don't feel as strongly with mental retardation, because the way I understand mental retardation is that it means that there's some cognitive impairment. So, spelling is hard with someone who's severely cognitively impaired, but

using a picture system and helping with the pointing I think would be very supportive.

22. Those were very good questions.

Subject #3

1. What type of degree do I have? It has nothing to do with what I'm doing here. Um, a biology degree from _____.

2. Absolutely not.

3. Uh, uh. No.

5. Go into it? The first day we learned about it, probably back in 1992, uh, we were sent home a note from her teachers that **N** had started doing this quite by accident. They didn't even think it would work with **N**, but they tried it with her, uh, they thought it would only work with some people with verbal skills, and they asked **N** questions. There was an article written on her in the newspaper back in 1996 about this wonderful breakthrough and that she told us where she lived and told the teachers where she lived, and that she used Tide as a detergent here, and all that, so she came home and I just sat down with her, and they just said all you've got to do is hold on to her hand and I held on to her hand and she started talking. It's no secret. **N** does it all.

6. Just with **N**.

7. Yes.

8. I don't know of any. We tried sign language with **N** years ago but it didn't work.

10. No. I'd never heard of it before.

14. It's hard for me to answer that, since I'm not an expert in the field. I would think it would work with cerebral palsy. I would think. Depending on the severity of the cerebral palsy. And certainly on autistic, non-verbal people. I don't think it's meant for everybody, and I don't think it's meant for strictly the mentally handicapped.

15. I'd never heard of it. I just sat down with her on the sofa like I am right now and started by asking her what her favorite color was and started learning about who my daughter was. She did all the talking.

17. Surprised? I've gotten answers that I didn't think, when I asked questions I didn't think would be her answers. I've been surprised when I've asked her questions and things like, "Well, what do you do when you just sit upstairs on the floor? What are you thinking about? And she'd say boys.

That would surprise me. I wasn't expecting that. Some of them I can't remember now. Surprised, unanticipated answers, or shocked? Never shocked. No, there's nothing shocking here. No, we've certainly not...and I've certainly asked her about misuse, people misusing N. There've been no shocking revelations, let's put it that way.

18. Yes. 'Cause I won't let her say it unless it is her saying it. And what do I mean by won't let her say it? It's because a lot of times if she doesn't want to tell me something, she'll just point to a letter and just keep hitting the same letter, like rr, or l,l,l,l and just not spell a word and I know she doesn't want to talk to me. But I won't force her as far as try to lead her to the answer she's thinking, or I'm thinking she might give me. I'm not leading her at all. I'll let her do it, and like the filet mignon story, I'll tell you right now. We were at the restaurant, oh, a week or so ago, and we were going to treat N and everybody, and of course I took the menu and asked N what did she want to eat? And thinking that N would pick, um, you know, would pick something simple, and she kept pointing to the filet mignon, and I kept trying to steer her away, you know, and purposely, 'cause it was expensive, and she kept going to it, so I bought her the filet mignon. No, and that really worked, because the menu, it wasn't really big, but it was a two page menu, and there were appetizers, and salads, and sandwiches, and there were some little entrees, and down here in the corner was this darn filet mignon, and I kept trying to go over this way, didn't I N? But N kept trying to, she was fighting me, and I'm trying to go over this way, and she's fighting me to go down this way. And you did it three times, 'cause you wanted that filet mignon. And that's what you got, didn't you? I don't know if you can see it or not, but, I don't know if you can or not...see, I can push her hand. There, I did it. I mean, watch her. "Nancy, do anything." I don't know if you can see her doing it or not, can you? I can feel her doing it, because I know I'm not putting any energy into it, and I can feel her. I can feel that motion just like if you held onto my hands, you could feel it.

Do you want to try to do some with [the interviewer]? Have you ever done it? Do you want to? Would you answer, would you answer a yes or no question for [the interviewer]? Alright _____, all I'm doing is putting my hand under here. Really easy, I'm not holding on tight. If she wants to answer, she will, if she doesn't...I'm not steering it, and a lot of time she'll miss. See now, I don't know what that is. Will you let [the interviewer] do it, hold onto your hand while you do it? She probably gets a little nervous when you're here. It's not you, that's what I think everyone needs to remember, it's not the facilitator. There's nothing magic about this. Now just take her. Probably be easier to use your right hand. See, look, she's wanting to do something already, and you haven't led her to it. Just take her hand, just like this, use this finger, and hold her hand where I'm holding her now. Well, let me ask 'em. Just, make sure she's got you hand, make sure there's contact. Yeah, put your hand there and "Have you done your homework tonight? Huh? Are you mad at Daddy? Are you mad at Daddy? Come on, you're not facilitating. Are you mad at Daddy? Is she just going back and forth? Can you say no? You're not doing anything? What's the matter? Are you mad at Daddy? You're not sure? Come on, now, it's okay. [the interviewer] just wants to know...Now answer it, are you mad at Daddy? **N**, say no, 'cause you're not mad at me. Can you tell her your name? Spell your name. Spell your name. Spell your name. Sometimes I get this, I mean, sometimes I get stuff that.. and I don't know if it's...I don't know what it is. I don't know why I get answers sometimes and why I don't. But why is she autistic? You know, sometimes she'll sit down with me and almost put her finger through the board and doesn't want to do anything. And yet, she tells me she'll do it with you, but then when you sit down and do it...I also don't know...See, she doesn't do much more with **M** than she just did with you. She'll do some stuff every now and then if she's in the mood. And I believe **M** believes she's doing it. I know I'm not. I wish there were some way that we could hook up electrodes to me, and hook up electrodes to **N** and we could determine motor movements, stimulus, or biofeedback, or whatever, and prove that it's her muscles that are moving this thing and not me. Um, it's also critical how much she looks at the board. You know sometimes if she's not looking at the board, sometimes she misses letters, you know. She'll be in between like this, and you don't know if it's a T or a U. How she feels, if she's frustrated or not. She doesn't seem to be frustrated tonight. Are you frustrated tonight? Why didn't you facilitate with [the interviewer]? Search for the answer. 3? That's not an answer. Do you know why you didn't facilitate with [the interviewer]? I don't know what she's saying. Spell a word that I'll understand. Did you make an effort to spell the word embarrassed? This is an awkward position for me. Um, what else? Do you feel like this is some kind of a sacred thing here? Is it a real personal thing, our communication? Hmm? Do you know what makes you facilitate with some people and not with others? Do you know? Question mark? I don't know. I mean sometimes, like today. The girl's smart as a whip. You know one day she'll...You know, one day in class she gets a super 100 on the work in Biology, and...where is it? I just saw it a few minutes ago. And then yesterday she does this. And it's a comment, "She could have done better than this. I don't think she was staying on task." 'Cause I know **N** knows these things. There's no question in my mind that she knows 'em. But yesterday was not a very good day. I don't know if that helps you or not. See, a lot of times we do a true/false. We just put a T and F at the top and **N** just points to the T or the F. I could make them further apart. I certainly don't have them close together like this. You know, where it's very easy to...but um, I don't know, I don't think there's much in here, except that F wasn't good.

I noticed you had an article on us. Where'd you get that? Oh, she did? Wonder where she had that. That was N's teacher. See, this was back in it was in 1991 that it happened. I don't know, this was, see "She spelled milk and I almost died." That was P, which was her teacher that didn't think N would do any of this. And she all of a sudden, oh, here it is on the back too, excuse me. I don't know, somewhere in there it's about me and "It's a miracle, Mr. D. said." The first night that I had done it, I asked here what her favorite color was, and it was pink. And I had no idea, because I had asked her red, black, blue, green, or yellow. What are the favorite colors, what is your favorite color out of those choices? And she at first went to P, and I thought, "Oh my God, she's gonna put purple." It was the first thing I thought of, and she spelled pink. And then I really knew, and see it says I knew it was real. And that was the first time I knew it was real. Because I got an answer that surprised me. Now you might say that surprised me. I don't know what you mean by surprised. But there's even some stuff about facilitated communication where kids have accused people of doing things, and you know...They wonder if it's not some fantasy or something in the facilitator's mind. I don't let her, I just don't try to make her do anything. If she's not doing it, you saw what you got. And when she did a little bit with you, she was just going to the board, just touching it with you. You know, it may just take a while for you to develop a little more confidence with her, get to know her, or more confidence in the facilitation. I think she has a sixth sense, you'd better truly 100% in your heart believe she's doing it. And I think that's what got me going with her. I came home, and I said, "Oh my God, sit down, and let's do it, baby," and she just started banging away. And I just said, "I know you're gonna do it." And I had no doubts, no questions at all about it. The reason I did this is because I'd always looked into those eyes, and I could always see her looking at me like I know you're in there. And I could see in those eyes, there just always looked like there was something in there rather than mental retardation. And I think this got it out, but is this going to work with everybody? No, and I'll bet it's probably less than 5% of the mentally handicapped that are going to be able to do it. It's a guess. It's obviously a guess. And it's a guess based on all the bad publicity we've seen on it, and um, so forth. And you know, even one guy did a study about asking the people...You know, they would show N a picture of a glass of milk, and then they would show me a picture of a bird. And they would ask N, what was that picture you spelled [saw?] and she wouldn't spell anything, or would spell something totally different like bean, and neither one of us had seen a bean. So, but then some of the kids were doing it, and they were spelling milk. So that's going, whoa, here. You know, something's wrong here somewhere. Um, there are times that she has such an open-ended question on her homework or something that I have no idea what she's saying or going to say. I know what she may be saying. Like when I'm asking her questions on that word, circulation. But I have had her say the wrong answers even though I've known the right answer. There is something in there and I don't know how it's ever...Well, Biklen just sat back and said, no, no, no, no I'm not going to do that. I don't know, he better do something, or it's going to be a dying art.

19. I only know my method. I only know what is working with N, um, so it's kind of hard for me to say, but the hand over hand, and going straight down in a vertical movement to a board or a letter really leaves a lot open. I don't even see the student or the...the person moving. You can see her moving. At least when she went to the board, could you feel her moving to the board? Could you really? Don't tell me that for my purpose. But it was hard doing the forward motion. Well, that's what I feel. Now when she really starts cranking out the letters and the words, her hand does, well you could see a little of that with me when I had her and she was deciding what she was going to say, and her fingers will do this and along with the movement. The movement is usually forward and the finger usually picks out the letters, not the whole arm. The whole arm doesn't move toward the F, and the whole arm doesn't move toward the A. It's usually the finger. So how many people admit it? I question the hand over hand. You can see that, if anything we're at a 30 or 45 degree angle with the board here and she's moving to the board, she's not coming down on the board, so it's much harder for me to direct it, especially when her finger moves. But if her finger stayed perfectly still, I could very easily, you know? But it's very easy for her to do that, so, I don't know, it all depends on the student you're working with.

20. Obviously, 'cause I know it works with her. I know it works because I've challenged it myself with her. I'll try to make her do things and she won't do 'em.

21. If they don't want to learn the answers. If they don't want to open up a whole new world to their child, I don't know. That's a hard one to answer. I really think, well, you know, you're asking me to name a label, and it's very hard to name a label, because someone that's mentally retarded, or however they're calling them now, mentally handicapped. Is a person with autism not mentally handicapped? In some ways. In some ways the mental handicap with autism is preventing the person from performing total normal duties all day long, and living in a normal environment like you and I do. So, is not this person mentally handicapped in some way? I don't know, it seems like so many overlying areas. You'll take some people that are mentally retarded, but show some autistic qualities, then you'll take N, who's labeled in some big realm of the world autism, but yet she doesn't beat herself on the head. Or she doesn't throw these big huge tantrums. Now wait a minute, I've seen her pissed off, pardon the expression. And she can get fiery, and she can yell, and she can walk upstairs and pitch a

bitch, but not like I've seen some of the autistic kids on those television shows. She's not self destructive at all. I don't know, again, it's hard for me to say that. I would think that if you had a person that's strictly mentally retarded, and I don't know how you'd do that. I would say it probably wouldn't work. Are they verbal or non-verbal? I mean, if somebody's pretty verbal, wouldn't that work? It does with me. I can spell on the board. I don't even need someone to hold my hand. So wouldn't it work with anyone that's verbal? I don't know. Did I answer that? No, I didn't really. Sort of did? But I'm not an expert on this method either, and since this method hasn't been scientifically proven to the whole population of handicap. How do I know which one works and doesn't work? With what groups?

Thank you. I just know it works with N and that's all I care about. I know she's intelligent and I know she's telling me things when she wants to tell me and when she doesn't want to tell me, she doesn't want to tell me. I mean, that's really all that's important.

No, just that I wish that Doug Biklen would get to do some research to prove the validity of it for the population that it works with. And, um, counteract some of the negative comments that we have. Yes, I would want him to do something. Because it's such a small area, and it's almost like I don't want to say I do it a lot now because so many people would say it's bad. And yet I know it works with N. But I think the general population took off and just said, oh, everybody can do this. And they started doing it with kids that can't do it, or don't do it. And then you had facilitators that were leading these people, and it may even be almost semi-subconscious, but they're doing it. And uh, and it should have been kept to a well insulated and well isolated population of the handicap community.

Subject #4

1. Okay, um, I only have one year of college, so I don't have a degree as such.

2. No.

3. Yes. (In what way?) I do vocational assessments for the _____ schools on the special ed students and I also work with parents who have children in special education. I do workshops for parents, answer questions when they call in with questions, we have a lending library for parents. Um, try and have several programs a year for the parents with a guest speaker, oh, and I publish a newspaper for parents who have children in special ed every six weeks.

4. Um, before the parent resource center opened, I had to have training, that was given by the department of ed and the parent educational advocacy training center out of _____, and they have continual training throughout the year, once or twice a year. And I go to these trainings.

5. Okay, now, the facilitative communication has nothing to do with my work here. The facilitative communication has to do with my son. But I went into the work here because I was interested in special education because of my son, and I thought it was such a needed service. Um, to work with parents who have children in special ed, because I know how frustrating it is, um when you cannot find the services that you feel you need for the child um, not necessarily in the school system, but when they are older and out of the school system, there are no services and I thought it would be great to work with parents and help them find these services so that maybe they would not go through some of the frustrating things that I had been through.

6. Um, LD, ED, EMR, uh, other health impaired, I think that's it, I also work with at-risk students in danger of dropping out of school. So I also work with at-risk, they are not, um, special ed as such, but i do work with them because they do have needs.

7. Yes, with my son.

8. No.

9. Three years ago.

10. Yes, um, J from _____ came for consultation with myself and my son's speech teacher, he was in school at the time, and my son, and spoke with us about facilitated communication and showed us how it worked. Um, we had sort of a private, mini workshop on facilitated communication. Uh, J began that day with my son, just getting him to point to pictures and then progress to maybe yes or no, and went to multiple choice, and before the day was over, he was spelling on his own, he progressed very rapidly.

11. Okay, now I am not a facilitator here at the schools as such, I just use it with my son. I had the private session with her that day, and I have been to several workshops given by _____ on facilitated communication.

12. Uh, yeah, he adapted very easily and quickly, so it was more than sufficient to use with him.

13. (Is it just with your son?) Yes. (And he's autistic?) He's autistic.

14. Sure, I think it would be valuable for anyone that had a problem with speech. A problem to the degree that, um, they were not easily understood.

15. No, because I didn't know that much about it to even have an opinion.

16. Probably almost every time we use it. (Surprised in what way?) Um, I've been surprised at some of the things that my son has said, and some of the feelings that he has, surprised at how deeply he feels, um, and uh, the emotions that he has.

18. Yes.

19. I don't know of any.

20. Oh, yeah, definitely.

21. I think if um, there is enough of a problem with speech that the person cannot communicate easliy and have his wants and needs understood, then I think it should be considered, I don't see any reason why it should not be considered.

22. I would like to say that when we first started doing this, um, my son's speech teacher and I were both working with him. And I think with everyone, there's always a question as to who is doing the communicating. Whether it's actually the person, so I made up a list of questions, and I typed them out on a piece of paper, front and back, so it was say, forty or fifty questions and had, there were no answers, it was just questions, and

he went to, the school that um, she was working in, she used a computer down there. And asked him the questions. They were questions that there was no way she could know the answer to. They were questions like, what color is your toothbrush? What did you have for dinner last night? What did your sister have on her T-shirt yesterday? What color is the carpet in your bedroom? And I think it was fifty questions. And he answered every one of them. And there was no way she could have known the answers. She had never been in our house and did not really our my family, and certainly wouldn't have known what color my son's toothbrush was, or what we had for dinner last night, and there was not one question that was incorrectly answered. So, That certainly indicated to me that that was my son talking, and not the facilitator. Um, in any way, even if it was unconsciously, because she could not know the answers. I have some articles on my son, would you like to look at them?

Subject #5

1. Okay, I have a Master in Education with a specialization in severe and profound handicaps, and I graduated in 1984.

2. No, I didn't go for certification. I planned to work with adults, which I do, and I spend most of my time working on employment topics.

3. Yes. (And in what way?) Well, I'm general manager of an electronics assembly business that we started in 1986 to employ a diverse workforce of people with developmental disabilities alongside co-workers who were typical workers. Um, We're private, non-profit because of being set up for that particular mission. and we get money from EDS, that's state and county money, to provide the support that is one of the models of supported employment. Uh, if you're familiar at all with the University of Oregon and the supported employment models, this was called the Benchwork Model. Sort of the idea of a small business. And we employ 9 people with developmental disabilities. If I had it to do over again, in this year, and with what I know about individual support and how successful people can be you know, I wouldn't start a business like this again. I think it's been a good demonstration, and good for the community to see people as capable. But, individuals need to be in the spot that's suited to them, with their own individual supports, and when you have people in groups of 3 or 9, it's harder for people to be individuals.

4. Hmm, goodness. And you want me to focus that specifically on working with people with disabilities. Um, you're probably not interested in my business courses. Um, everything in my Master's program and my undergraduate program, we had a strong concentration in psychology and human development. Uh, in my graduate work, I can't think of anything that didn't apply. I had language development, and augmented communication, and behavior modification. Well whatever they were calling it then, which was probably uh, what was before functional analysis? Uh, adapting instruction, just you know, vocational methods. You name it, it all really fit, particularly when I was focusing on adults.

5. Um, I found it really, really interesting. Depends on how far back you want to go when you say, "go into this type of work?" The reason that I left, after I got my undergraduate degree, that I started working with people with disabilities, was that was 1979, and there'd been a lot of talk and movement about getting people out of institutions, and that was on the national news and something I had heard of, and I'd started out in college as a home economics major, and, partly because of the issues of quality of life. That seemed to be, working with people with disabilities and helping

them move into their community, and have, you know, regular lives, sort of was a way to blend, you know, my background in psychology and human development. And that early interest in the practical aspects of how do you make life work? I saw them as problems that we looked at actually in home economics, strangely enough. And I knew it would give me a chance to decide what I wanted to do as far as going for a Masters degree, to specialize in some field. There's an institution in this area that does a lot of hiring, and that was a place where I could get some experience, not necessarily good experience, as it turns out, but experience, and after working there for a while, and finding out that people's lives were not what I would want my life to be, and I didn't see any movement at that time in really moving people from the institution into the community. People with more significant disabilities were staying in the institutions, and they were going nowhere. Um, I had a friend who got involved in vocational training and uh, left _______________ to work there. And she was a person I learned a lot from, she had a degree in special education from ____________. ...knew a lot about task analysis and adapting instruction...very creative. And so, partly it was the chance to work with her again and do some curriculum development for adults. The reason that I am no longer there, in employment, is because again I saw people in dead-end prevocational situations where they were never going to get jobs, and, and uh, they would get to retirement age without ever having worked, and I didn't want to be a part of that, I wanted to learn what else to do. And so I went to graduate school to focus on adult issues and employment issues, and then had the opportunity to start a business, and got the training to do that too. It's one of those things where I wanted people to have that opportunity, and this seemed the way to do it sort of, but I had to do it myself. And there was a lot of support, you know, locally. It's been real interesting, because it's um, and there's an aspect of social change. And, um, you know, this has been called, people with severe disabilities have been called the last disability, the last minority um, and there are a lot of issues that are the same, that you found in the civil rights movement with black people, it's just been a lot of issues with people trying to be self-determining, and get control of their own lives, and be appreciated and have opportunities to grow. I guess in my background, I realize I had a lot of those opportunities, and it struck me, when I began working with people with disabilities, because I had never grown up around people with disabilities, there's no one in my family who had a significant disability. Um It just occurred to me that, um I'd had a really good opportunity to get a good education and to grow up in a community where the people with really significant disabilities who were born the year I was weren't anywhere for me to see them and to grow up with them, and that didn't seem right. And so doing something to change change systems, and give, you know the opportunities people had in the last sense. So there's that appeal. [Had difficulties with the tape recorder, had to stop it for a minute. Nothing was said relating to the interview at this point. Started recording again and asked, "Was there anything else you wanted to say on that question?) Um, well, related to this, why I stay in this work is, it's really interesting and uh, it's, it's sort of taking on a lot to run a business, and deal with all of that and payroll and everything else, and to incorporate people with disabilities, that it's been real interesting, and we've had really good staff to work with, and , and, our employees have been much more accepting of people with disabilities as they've gotten to know them and I guess it's my focus is not just a demonstration project and what's happening here, but looking at the whole community and how can we have an influence on the whole community, so that people know someone with a significant disability, maybe with the label profound mental retardation, can be successfully supported here, or we have nine people that we support here, and maybe their business could support one, and we're hoping that that we'd have the opportunity to share some of the things that we want. And we continue to learn, facilitated communication has opened up a whole new way to, you know, allow some people to communicate and to participate in the company in ways that we had no idea they'd ever be able to. And we were fine with that, we just had no idea that we could have company meetings where everyone might participate.

6. Um, people with um, physical disabilities, autism, well, I guess physical multiple disabilities um, labels of severe and profound mental retardation, um, multiple disabilities, like profound mental retardation plus blindness, sensory, various sensory disabilities in addition to some level of mental retardation. (And have you used facilitated communication with all of them?) Uh, let's see, the person with cerebral palsy has used it with some other people and I haven't used it with him yet, he's getting a he's been using other kinds of systems, and has intelli...,somewhat intelligible speech. But its real limited, and he's thinking about trying some level of facilitation. He'd be a natural, but we really leave it to individuals to give us some indication of that, too. I've talked to him about it. With the first person, that we used it with was someone with autism who had no speaking ability, can make some sounds, but not clear enough. And it was someone who was doing some really challenging things that were puzzling to us. And, um, was doing some things that were dangerous to himself and us, and we were looking for anything that might enable us to get some communication going with him. And my ultimate hope was, if he could answer yes and no, we could ask him anything in a yes/no question. And that that would be some progress, because we were really at that level of not, and not sure that would work for him. Um, he had been assessed by someone who was a specialist in autism, who said he needs, he doesn't understand how to point. And had suggested that we present him with say, a brush, and a Dr. Pepper, and ask him to point to which one he

wanted, and help him through that pointing process. What we found was, that that was real frustrating for him. And he didn't care to sit through it, and he still had the difficulty pointing, and we got training in John McGee's Gentle teaching, initially before we actually got training in facilitation. Just to see if there was some way to form a link with him. And we really only want to use very positive approaches, and uh, non-aversive, the most positive approaches, and that was one. But the facilitation worked with him, but it didn't work fast, and it took two of us, working almost daily, Monday to Friday, watching each other, comparing notes, seeing what worked, for three months before we saw any possibility that this might work for him. So it was a long haul to even get some results at all, that started to look like maybe he would use the method. We've used it with other people who have a label of profound mental retardation due to unknown cause, injury at birth assumed. With a lot of adults, the labels are fairly undistinct, syndromes aren't necessarily defined. Um, on one occasion, not in my work here, but on one occasion, I did facilitate with a woman who had a stroke, who had facilitated successfully with at least one other person, and she wanted someone else to do it to compare, to feel confident with what she was seeing, with what kind of support was needed, and it was only on one occasion, but the woman was interested in doing it, and appeared to be making a lot of effort, and she may have given me a message that was coded, but it was hard to tell, so I didn't have enough experience to say yes this works for this woman, but it was intriguing a method, if I knew here, I would keep trying. Um, I'm trying to think if I've used this with someone who has Down's Syndrome. Um, I have a little. Some people we've just started. They've used other methods, and are coming to us, and we, for the person who has a lot of challenging things going on, we felt the need to really try all kinds of methods pretty actively. And with other people we don't push it as much, because once the person decides they want to use this method, things progress really differently, rather than if its us trying to get the person to try it, and maybe they're not interested yet. People who have some speech have tended to take a longer time to make up their minds sometimes, of whether they've wanted to use it. And, um, I'm trying to think of any other labels, not a lot of specific labels, there again, I think it's probably because adults don't you know, I don't know any adults with ? syndrome or any of those other syndromes that you hear.

7. Um, yes, uh, on a daily basis, I facilitate with several people, and one of the individuals I used to facilitate with, moved out of the area, so I just don't see him. Um, there are two people here who use it a lot, one person has speech, the other does not. Well, the other person is the first person I ever learned to do facilitation with. The other person is someone who has limited speech, his label is severe mental retardation, no particular etiology. Um, the speech therapist recently started an evaluation on him.

Says it's real clear that he has a lot of motor planning problems going on, but she hasn't finished with him, so I don't know if she's going to have any other statements about his abilities. But, um, with those two men, I do often, if not daily then almost daily. With one of them, pretty much daily, he seeks me out.

8. Mmhm, you bet, concrete objects, in fact that was what we tried before we knew about facilitated communication. We tried concrete objects particularly here and in work situations, we wanted to know "What do you want for break? Where would you like to go for lunch?" And to get people to thinking more about spending their money, so they could make more money to spend more money. And just making choices so they could have more choices in their lives. So we've tried um, laying out objects like Fritos and corn chips, you know that kind of concrete object choice, or two different kinds of things to drink. Or, uh, a menu from...or something that tells...a picture of MacDonald's, photos or whatever. What we found was really difficult was there were people who couldn't consistently point to objects. They'd point to both. Every time you'd put things out, they'd point a little more to one than the other, but they'd point to both. We didn't know what to make of that, but we couldn't use a lot of the picture systems with some of the people who were having a lot of difficulty communicating. I think a lot of people who work here were selected to come here because they didn't communicate very well, and did a lot of challenging things, and that's who we specialized in. So I think that's sort of pre-selected a group of people who we employ to be more people who didn't communicate very much. And more people who did challenging things. Some people, the people who speak more here, have been less likely to use facilitation, to try facilitation for very long. Um, one person quit altogether, she tried it for a while, it was really frustrating that she couldn't do it independently and she quit, and uh, hasn't done it again, although she spent a lot of time with a typewriter, trying to to do it herself, but hasn't had any success. And I haven't had any success, when she was interested in working with me, didn't have any success in "touch a letter, touch the table," just to give her that process that would make her scan, and be able to do it more independently. But if she wants to come back to it, she might. But we have Myer Johnson symbols, you know, the whole system for that, and we use those often for people. What we find is that in employment, Myer Johnson symbols don't take you real far, so you might have to use real pictures. And uh, a lot of times, the things we're dealing with aren't always concrete, and there's not always a good picture for something.

9. I would have to check back on the date for that. I can't remember if it was '91 or '92. Okay, I started using facilitation in 1991. I had training at Syracuse University. Their uh, two day training seminar in August of '91.

Oh, and you were asking about augmentative devices. Uh, I worked with someone, actually several years before I started __________ who was using a Cannon Communicator to spell independently, and rebus symbols, rebus books, some of those that we pretty much assembled ourselves from the rebus system. Uh, Intro Talker, Alca Talker, and just communication boards, um, and not only augmentative systems, but really a lot of gestural systems, sign language, uh, worked with a woman who used finger spelling and Braille, but I, I was, actually I didn't work with her on the Braille. Um, the individual that we went to Gentle Teaching to learn about and we finally ended up with facilitated communication working, because he actually could spell. Um, we actually used like a hand-gesture system, um with him, because he would give me five, and what we found was that, whenever he was having a problem, or whatever, we'd offer our hand, and or say "How ya doing," or whatever, and he'd use variations of giving five. Like, if he was really upset, you might get hit, or really hard, or if he was feeling really good, it would be sort of smooth, and it was really interesting how he was using that to convey, and over time, in addition to using the facilitation with the typing, he uses like a gimme five with his palm down, for yes, and the back of his hand for no, and he has difficulty retaining consistency with that sometimes, but when he's using it a lot and you pause before, between the time you ask a question, and you offer your hand, so that he has a chance to think rather than just doing an automatic response, then he's pretty consistent with it. And it's been and he's trying more and more to talk, so sometimes when he's trying to say a word, it's a little clearer or when he's typing he'll say the letter, cause he can say the letter "t" correctly, so when he's' typing he'll say "t", like I said, it's real interesting, so anything that was out there we were trying to try.

10. The only thing that I had was a flyer in the mail telling me about it. I received a flyer in the mail, cause I'm a member of TASH, and AAMR, and CEC, several things, and I got a flyer in the mail, and I just looked at it, and this person that we used facilitation with has, had autism, and I didn't realize that it might have use for other people, but, it was worth it to me, to, basically I ended up paying my own way to Syracuse, 'cause the company didn't have that kind of money, to learn it, hoping that I might learn something to help him. Before I went, I um, asked some other colleagues, whose opinions I respect, and who I thought maybe had heard of about it, if I hadn't, and one colleague who had a brother with autism, had spoken to Rosemary Crossley and had looked into the method for maybe using it with her brother or someone, and said it seemed to have merit, and it was worth looking at and that's, you know, so that's why I went to Syracuse.

11. The training that I had was a two day seminar, tons of reading material, all of which I read, there were videotapes on what the method looked like. They showed the initial videotape of "I'm Not Autistic On The Typewriter."

We had lectures, discussion groups, some hands-on training with each other, and the topics that were covered had to do with hand function problems um, why facilitation might work, and the idea of some kind of global apraxia and motor planning problems that people with autism or other disabilities might have. The interesting thing with that, is that connected with something that...and I've been working in vocational training in various settings with people who have significant problems performing frequently use hand over hand training methods, and it always, it started to amaze me after a number of years, prior to FC that a lot of folks would be, that had evaluations from schools, would be, "Oh, I have excellent fine motor skills," and I would find they didn't have excellent fine motor skills, they would have pretty good fine motor skills, you know. Things that they did a lot, then they might have really good fine motor skills, but when they were trying to learn something new, it appeared there was some difficulty getting their hands to do what they want that was beyond just not understanding it in their head. And I'd seen this across a number of people and it made...and this one individual , the second person we used facilitated communication with, it was real interesting. We had noticed that he has trouble getting started moving, and so we would set out these two concrete objects, the Fritos and the Chips, you know, "Which one do you want for break," and he would just sit, he wouldn't do anything. And we finally got to the point, we'd tap him on the hand and then he would move his hand and take one of the items, and then we would notice, he tends to move his hand and touch whatever's straight in front of him. So you have to not put anything across midline, cause he's never going to get that, you need to put 'em not too too far apart from him, and you need to touch his hand if he doesn't start right away, and some of those things connected with the whole idea of having motor planning problems, and I thought, "That's interesting." And, uh he was actually the second person we started using facilitation with, there again, people who we had no other method, and we were struggling with what methods we had available. That got away from the subject of what kind of training I had, I don't know how much detail you want me to go into as far as what topics were covered, or...(Whatever you want to cover.) There are presentations by a number of people uh, Doug Biklen was one of them, Annegret Schubert was another, and then teachers who had used the method, and who had been involved in the initial research, um, that uh, Doug did in Syracuse, uh, some of their families were there. We also, we saw typed messages, and all their messiness and misspellings and whatever and the ways that you would try to clarify, what does this really mean, because when there are a lot of typos or even just one typo, you can have a very different word, and a very different meaning, and so there was focus on clarification techniques, and um, a lot, and you could certainly have spent two weeks with that information I'm the kind of person that takes everything and reads, it, if you didn't, I think there would be a..you would have a lot of questions, we also, uh, had a long list of resources, and I kept up with newsletters, and things to keep current on the technique.

12. I felt that it was sufficient to give me the start that I had, but there are all kinds of ways to rate that. Um, I started, out, I had a background in teaching, and I had done lots of hands-on training with people. And, this connected with some things I had done. It was very different from hand over hand, you know, where you're guiding people. Um, from the background that I had, um, it wasn't a terrible stretch to take on a technique like this. Um, what I was able to do, though, and what helped, was that I started with one person at the same time someone else did and we did it together, and we compared what was working and what wasn't working, and it was probably good, that it took us a long time to have success. Cause it made us determined to just keep trying, nothing else was working, we might as well, nothing to lose, maybe something different. Um, I think it was, it gave me plenty of background, in fact, I have done training, but I didn't do any training of other people until I had started it, done two individuals from beginning to success, and uh, actually at that point, when the first person had success, after three months, well, actually after he had moved to fluency, or just, I guess he had gone to fluency by the time I got in touch with J.J, at _____, he had gotten to fluency, and the next person had, not gotten quite to fluency, but close. And so I called my professor from _____, and said have you looked at this method, you need to look at this method, what do you, you know, what do you think about it? And she had been looking at the method, and hadn't had a chance to do much of it, they had training, so she and I did some trainings together, and you know, set up a curriculum together, and did some trainings. Um, what I felt was needed was having support, I'm general manager, no administrator was going to tell me, you can't do this any more. Um, I had enough other people, in addition to the one person who was here, other people in the area, who were doing the method, and we formed a support group, and we met, for a couple of years, we met about once a month, and we talked about what's working and what's not working, you know, what are you doing, try to share ideas, and and whatever, and that was helpful, so I wasn't on my own doing the method, that's real key.

14. I think that it's too early to say, I think that it's something that, well, there again, with adults and with a lot of people, we label people that we don't necessarily know all the issues that are going on in their disability. Uh, I've seen motor, motor issues, in people who have autism who have all kinds of labels, that are mostly just a label they get because of, you know, flunk an IQ test bad enough, they just sort of hit that range, I have had success I guess the people I've had success with have been people who...and

people who've had other facilitators who've had success, it wasn't just me, people with autism who speak or don't speak, uh, people with severe and profound labels, or moderate who may speak or may not speak at all, people with pervasive developmental disorder, which is akin to autism and a lot of debate there, and Down Syndrome, I have friends who are facilitators who work with younger people who can list lots of different syndromes. I think the whole issue is here we don't know, it's too early, and I don't think it's only for people with autism, 'course people with autism aren't one, they don't have one thing anyway, there are lots of different symptoms, and no two people with autism are necessarily that much alike um, I dont know, I followed the research of Anne Donnellan and Martha Leary looking at the whole issue of movement difference, or movement disorder, but now they're using the term movement difference it may be that , you know, over time as our assessment methods get better that we'll get more at what some of the key issues are that people are dealing with and who facilitation might work with. Um, the state of assessments at this point is not wonderful, there are a lot of limits in assessments, and standardized assessment, I think one of the problems, one of the problems that a lot of people have had, is real interesting, at the presentation I did talking about facilitated communication, someone said, "But, if I have, if I'm working with a person, who, I mean, a psychologist has said, it's in the file, they've said, this person is profoundly retarded then they are, aren't they?" And you had to sort of find some common ground of understanding, and she didn't know where, where a test score comes from. And when we talked about that, the kinds of tests that we give people who don't communicate very clearly, or very much, have to do with movement, and if movement is part of your disability, but it's really not recognized 'cause we haven't really recognized it yet, then we're really testing your disability. And we may be missing something like we did with people who have cerebral palsy for years and years we missed something, people who are deaf for years were misunderstood too, a lot of times people don't know what we don't know as a field, and they make blind leaps, or without just ignorantly do something that happens to be good practice, or do something that happens not to be good practice.

15. I really didn't have any, because I didn't know much. I mean, basically, I had this little flier, and a real, a colleague who is one of those people who's out there on the cutting edge of supportive employment, and other things, and who, uh, you know her opinion was that it was worth looking at. And that's really all, all I needed.

17. Oh, yeah, I think that's why it's so difficult for people to accept, because there are things that are surprising. One person that I, well, both people that I started facilitation with, one I'd known, been around, provided support to, for over two years, and I didn't know what was going on in his

head, I couldn't, so when he started saying things , cursing me, it was sort of surprising. I don't use the term F-you and I was a little surprised to see it once. You know, was that really it? And so I clarified a lot of things, because I thought, "Was that right? Would you have said that? Did you really say that?" So, I think whenever someone communicates to you who hasn't, whether it's a typical worker who's just a quiet person, you can be surprised, and so certainly things that people said were surprising. That there has been controversy over what people say, is not a surprise. That people, uh, thought, "Well, I know Judy you mean well. You're trying really hard." But they were thinking, "She's really probably not right on this one. But, I don't want to tell her to her face." That's not surprising, either. It's...but you don't know, and I guess if you're someone who sees that, who realizes the limits of where knowledge comes from then you realize that something could happen that could give us more knowledge.

18. I think everything's not that black and white. I think that, if you look at communication, as not a clear process, and as a manager, I know communication is not nearly as clear as we like to think it is. When the words come out of my mouth, they don't necessarily end up in the head they're going to in the form I meant. So, um, recognizing the complexity of human communication, that's not an answerable question. I think that, I don't always understand what someone is trying to say. And, sometimes I try to get them to clarify it, and sometimes we never get there. I'm not confident that I really understand what they say. Sometimes, I've thought, "Oh I understand what this is," and I've questioned further, or made other remarks, because we were in conversation, which showed that I really didn't understand what they meant, and I've had to, I had to check. Uh, I ask people, "Was that your word or mine," if I think maybe, you know, I didn't allow their hand to move, you know, we were fading, but not faded back you know, real far. There are a lot of words that are one letter off of other words, uh, you know one letter by having an extra letter in it or not, makes it a different word, or the pattern of words uh, if you want to type the word J-U-D-Y or J-U-S-T, on a keyboard those are really close. And so, I think that a lot of times things come out that aren't what the person meant. Words come out of my mouth that aren't what I mean, too. And so I think you have to look at that process as, as that way it's communication, it's not necessarily what the person meant. If I were gonna act on something the person said, I would want to make real sure, and I think it makes sense to have the person express that to another person to be sure. But I think you have to go into this process explaining that, "I'm not sure, I may get in the way of what you're trying to say, or it may not come out like you want or you know, I might move your hand, I don't know, you know, I'm gonna try not to," but I give people ways to tell me that. I don't have a letter board in my pocket, but the letter board, one of the portable ones I use has a couple of things on it that the person just has to point up

there that says "You moved my hand." I figured that, you know, I want to know it. I want to be the first to know, not the last to know if I moved your hand, or if that's not what I meant, or you know, I don't understand. I could pull one out to show you, I've got all those little things on there, because I want people to tell me. And to me, making mistakes and correcting them is something that's going to be part of the process, and you want people to know it's okay. And then some people who didn't like to admit to a mistake, then that makes it really complicated. Um, one of my versions that's set up like a Cannon Communicator, is um, one of the persons that I work with daily uses a Cannon with a P offset here. So we've got wrong word, so if, either they typed the wrong word or I understood the wrong word, I can do that. If they just automatically completed a word, like an automatic completion or in a sentence, and that wasn't what they meant, I gave them that, that's not what I mean, you moved my hand, um, you know, I try to give, you know, as many opportunities, and I talk about these and and if someone's not correcting themself, then I figure I should work on that, so I work on that, and so one person I work with will spell out a word and then he'll spell out not in that same word and so when someone's using correction procedures like that, then I have more confidence that he's gonna care enough to get the right word out. It takes an awful lot of energy and concentration for the people I know to be able to do this at all so to correct something is a lot of effort, so I try to make it as easy as possible, and that's part of the process. Oh, I've also got a Dimeon spell it. And it was like, that wasn't part of it, nobody was using that very much and I just want to be sure if I'm moving somebody's hand I thought well, I mean, I feel awful if somebody points there, but in a way I feel good because I want to know. 'Cause the person I'm facilitating for is really the best judge of "Am I doing a good job?" Uh, course that's a whole different realm for evaluating facilitators, but I think well get there.

19. It's hard to say modifications, because I think the use of the method is not universally the same. I think what, what is most helpful, and we need to use, and I think there are a lot of things that I've seen that were most helpful to me and I think a lot of people see those same things so we ought to talk about continuous improvement and what are those things that make this process better. I drew up a list a couple of years ago, and I was just looking back at it today, and making a few changes, because I'm going to use it on Monday I'm gonna be training a team of facilitators for a little girl, and I wrote a list of what does it take, what are things that are helpful in developing your skills as a facilitator? And then the other side of it is what are things that are helpful to the FC speaker in giving that person the opportunity to develop his or her skills? So I have these two lists and I guess it would be, I'd like to talk about some of those things, I think I'd also like to talk about situations where you set someone up to fail. You set a facilitator up to fail, and there may be situations where this didn't happen,

but you're really asking for it. When you have someone use any method that's new to them or that they use in isolation from anyone else, and they have no support, no one's technical support, no one who can help them improve and an environment where people are looking at this method and saying, "I don't know if it's real or not. I don't know if you're doing all of the typing or not. Then you have a facilitator and an FC speaker who are headed for some kind of potential catastrophe. Um, no facilitator is perfect. I've had people tell me, I moved their hand or you know, I've said, "Is that my word, and I can't remember if anybody said, "Yes, that was your word." But they let me know in some way that it didn't come out like they wanted or that whoever was involved, it's a pair it's a pair working, and what you're trying to find out is, "How does this pair become effective together? And it may be that he or she is doing the best they can and I'm doing something that gets in the way and I have to get, I have to gain my technique, so from the moment you leave a seminar you're not necessarily an excellent, experienced, skilled, flexible, resourceful facilitator, any more than you are, you know, that kind of teacher when you walk out of graduate school, or walk out of school with a diploma. People need to look at it as a process of improvement, and administrators, I think if you have administrators who haven't used the method haven't looked at it real closely, and done a lot of reading on it to understand how does it work, and then listen to the people that are trying to use it with this person to find out what support is needed and what's not, administrators have kept an arm's length then there not any help at all, and um I just don't, I think this is too critical, that if the situation, for someone to be able to communicate their own thoughts, and experience all the growth that is possible once you can communicate when you weren't able to, and for some people that's literally what was starting to happen, they were communicating at a level that was yes, at least yes and no and nobody could get that before, um I think it's, there's too much at stake, and there's too many ways this method can go wrong. And make, either make the teacher look unethical, or whoever, make the facilitator look unethical or misguided, or something, or can make the person who's the speaker look incompetent. Um, I mean, you need a team of people, and you need that administrator's support because they need it so much, so you need practice you need...I've got a list, do you want a list, a list of things I've found. Um, I ran this off if you'd like to have it. It's not just an attitude, but there's an attitude involved, because there's an attitude involved as a coach or a teacher or helping anyone succeed, um, you can't, I think doing it in isolation is something you wouldn't want to do, but if you felt that that were really the right thing to do because someone needed it, Um, you know, it's a risk, but some people will do it, and I think some people have fairly bravely, or maybe just fairly ignorantly done it, in isolation without the support of other people, and ended up in in real tragedies. And, uh, systems shouldn't let that happen, they should support people, and what happens is systems have shut things down, and uh, that's, that's a big mistake.

20. Yeah, yeah, as long as the people who I provide that support to choose to communicate that way and yeah, I will. And that's part of the support we provide, is whatever support someone needs and uh, if someone chooses not to, yeah, I mean I'm not gonna force it on 'em. Early on in the process though, someone who has a lot of motor problems might not be able to make it real clear whether they've had enough for today or whether they need some help in relaxing so that they can go on. So there are people who can be read as not being interested when they're having difficulty relaxing and getting their motor movements together, and I think you have to be careful to be sure you're trying to understand what the person wants.

21. I'm real open, because I think it's just part of total communication. And I think that your goals for someone would be what you want. You want to be able to express you know whatever, so as long as someone has communication that falls short of all the full functions of communication being able to um, to laugh, to joke, and to make comments or to talk about emotional issues, or talk about the news, or whatever is typical. As long as someone doesn't have that opportunity, doesn't have that ability then you want to look at whatever system you're using and keep moving toward more opportunities for them to express what they want to express. If they're not, if symbol systems aren't working for them and you can try, I think facilitation is one of those things you could try, and evaluate. If you can have an occupational therapist look at hand movements, and hand function, or a variety of those things, that might be helpful. I think you don't rule out anything, uh, 'cause you don't know. Even Donna Williams, who speaks wonderfully, uh, I don't know, do you know Donna Williams? She wrote Nobody Nowhere, and her next book was Somebody Somewhere. And she has a book coming out next year called Like Color to the Blind. Which should be even better, uh talking about what her experience has been. Even she says that facilitation helps her type. She can type without it, but if she has facilitation, she can be much more focused, and much faster. But she said a lot of really interesting things when I heard her speak last, about difficulty she has that have to do with touch, that open up a whole new realm of questions about what facilitation may do. She says, for instance, if she's...or it has to do with touch or interaction, if she is concentrating on what you're saying then she cannot be concentrating on her reaction to it, okay. Or if she's thinking about what she's saying she cannot be concentrating on you. If she's very in tune with you, she's not in tune with herself and what she's thinking and feeling. And touch may, may be a problem there, because touch might make it harder for her to be in touch with what she's thinking rather than being in tune with you. Which could, makes facilitation somewhat more

complicated than we though it might be. So helping people establish their own voice, and consistently, I think is something that we need to do. It's not just can a person type whatever but really developing an independence. It's not just the physical independence of I'm not at your hand, I'm at your elbow, or I'm not at your elbow, I'm beside you, but really speaking your own voice, which has to do with people being willing to speak up for themselves instead of say what they think you want to hear. So it's, it's uh, complicated.

22. I'm hoping that, um, the field will look at what's coming out of Don Cardinal's research, and people who are looking at the whole process and people who are probably coming out with more questions about the process, rather than saying black and white this doesn't work. I think it's interesting that his research showed the same thing that the other research showed, that in the initial, in the first trials, nobody passed. But instead of stopping, they're saying, "Oh doesn't work, can't do it, these people can't do it. Let's give them counseling because they've been living with a delusion for a year like the people in New York um, and forget this person with a disability because they weren't really going through anything anyway." Um, I'm hoping that they'll look more at that and look at what does it take. Granted some people have have successfully passed, so I think the question of is this a method that can work for someone on the planet, that's been established. Yes, I think it can work for someone on the planet. And the question is who are those other people, how do we find that out? And what are those situations when they can, you know be in tune with themselves, and say what they want, and what are situations that make it more difficult, and how do we, how do we help them get skill, how do we help facilitators get skill? And how do we do it all together, and how do we help people who've questioned this and had a lot of things to say that, and you know, the debate's been nasty, on all sides. Um, I hope that we can all find that common ground and uh, I think that there's just too much at stake, and I think everybody does. I think Howard Shane thinks, you know, is very serious about his concerns and I think you know, people aren't in human services because they don't care about other people. Um, I think we'll find common ground. I think it'll take a long time. It's like the civil rights movement, you know. I remember sitting at dinner in 1972 with my husband, the year we got married shaking our heads at things that older people in our family had said about black people thinking goodness, how many generations is it going to take before we really have the world we want, and I think that people with disabilities or with new techniques or whatever, it takes years and generations longer than I'd like to think it'll take. But I talk to people who use facilitation about this before we start, and I talk to them about how, "You know that there's controversy, and people are gonna wonder and so part of what you're gonna have to work out with me or whoever is how are you gonna establish that it's your voice.

You know, you have to be up front with everybody, and you have to warn people, it's hard to be a pioneer. It's hard to be the first people doing this, or among the first. Um, but I, I think we'll find common ground. It'll take a while.

Subject #6

1. Um, I have a Master's Degree in Education, I got it at _____. I have a BS in, I guess it's Education from _____, and I'm endorsed in mental retardation and emotional disturbances.

2. Yes. (In what areas?) Mental retardation and emotional disturbances K through 12.

3. Yes, now it does. I'm a consultant now to school systems. (Okay, and what do you do?) Um, I go out to either a whole school system, and we talk about a systems change, or I go to one classroom and we talk about that particular classroom, or I go see one student, and uh, we work on that student, and I work in the areas of curriculum, behavior management, communication, um, managing health needs, what else am I doing this month, those are the general areas.

4. (Paraphrased from phone conversation.) Practica associated with classes she was taking. Worked at _____, with autistic children, _____ with autistic adults, and worked at her campus school for students with special needs. Volunteered at a summer camp for people with mental retardation. Also took a Diagnostic Reading Class, and Behavior management class which have helped.

5. Um, I, I just, I went into teaching because I like working with students with special needs. I'm doing the consulting now, because I can't teach everyday and have five children at home.

6. Um, mental retardation, severe disabilities, emotional disturbances, autism, mulithandicapped, deaf-blind, orthopedically impaired, uh, deaf, I think it's almost every group.

7. Yes.

8. Yes. (What kind?) Computer assisted instruction, computer assisted communication, um, word, just plain old word boards, sign language, sign language that was invented specifically for one child, picture communication systems, um, baby talk (this was a joke, because her baby was babbling) I'm trying to think what else we've used, we've used some, most communication systems that I've set up have been set up specifically for one child and would involve whatever vocal abilities they have, as well as if they can do dome sign, we'll use sign, if they can use gestures, well use gestures um, I have never used Bliss symbols although I've been involved in classrooms where they have been used. And I don't, at this

point I don't generally tell people to do sign language unless they're in an environment where it's going to be understood.

9. Oh, let's see, nineteen ninety...let's see I was pregnant with somebody, 1992.

10. Um, I did a six hour training seminar, and then I observed for three days, Syracuse came down to ___ and uh, I spent three days doing one to one consultations, and I was working for _____ part time at that time, and so I ran the cameras for them and observed that, and then uh, I got all the literature that they had at that point, there were a couple of books out at that point, and I read those and then began tentatively.

11. (Okay, so that would include your training then. That was your training for it?) Right, right initial training, now I'm, I still go to...Syracuse has a yearly seminar and I go every year and um, they, they have in Jan they have advanced training, that thus far I've been unable to get to, but I'm supposed to go this year, if everyone will stay well.

12. Um, probably not if someone were just gonna just do the six hours, and then observe and then go back to the classroom. Part of, part of what made it different for me was that after doing that and then working with students is that I was going back and talking to the folks that we met at Syracuse about, now wait a minute, why was this, and have you done this and has this worked, um, and I started very slowly with one student and then another two months later another student. Um, with the idea that I just, I needed to gain experience with it before I really started doing lots of stuff with it, um but if you were just, if you were gonna do it with your classroom, and you were only gonna see your group of kids you probably would either need on going support, or maybe some more, more workshops dealing with specific classroom issues, um, yeah.

13. Um, students with autism and students with a label of severe mental retardation, and a few students with uh, physical impairments, and their cognitive impairment was questionable, no one knew.

14. It's, you know, it's hard to label the population. You know, they talk about kids with autism, and you see kids with autism and depending on who's diagnosing them, they all look different, they all do different things. Um, kids with severe mental retardation, if they were looked at by this person that person would say autism, if they were looked at by this person, they would say no it's not autism. I think any child who cannot communicate verbally or effectively verbally, that anything, any kind of communication any kind of augmentative communication system that will help them communicate more effectively should be tried. And including facilitated

communication. The problem with facilitation is it's just not the best system. I mean it's a good system if you have nothing else, but it's certainly not the best system. You have got to have someone with you, people don't always believe in it, it's easy to be influenced, so you're really not getting your message across, I mean it's filled with a lot of problems just as a lot of the assistive technology things are. Its slow, it's cumbersome, you know, but for anyone who's not communicating effectively, we need to find a way to do that and if facilitation is the most effective way, then that's the way we need to go.

(Do you believe that there are any populations who should not have, um, who should not try facilitated communication?) Well I used to think people with Down syndrome. No, I don't think there's a population that shouldn't try it, I do, there have been a few folks that I've worked with that could facilitate, but it was so very slow, that that I recommended they find something else, and gave them some ideas of some other things. Um, the problem is that there just aren't, if you've got a kid who can't communicate, there is no place to go that , you know there's just no, you know we talk about oh we can make assistive technology work if you can just blink an eyelid, so where are those places, and how can ordinary Joe parent take their kid there? I mean that's the, that's the bottom line. There are kids who can facilitate but for whom it's just not going to be an effective method of communication. I mean parents know what they want, so they don't need to spell it out, they just kind of know.

15. I had heard of the method about six months before Syracuse came down, and had scheduled to do, there was a conference in, somewhere that I was scheduled to go to, and got sick and could not go, and at that point I was interested in hearing more about it Doug Biklen is certainly one of my, when I was in school he was the name on all the textbooks, so I was interested in hearing more about it because he was talking about it. Um, when I went to _____, when the Syracuse people came down, I was interested, and a lot of teachers that I knew that I respected were saying yeah, there's something here that you should go and see. And so I went down willing to believe something was going on, but certainly not willing to, certainly not knowing that I was going to change a lot of my beliefs.

16. Um, I think, I think one of the things, and this is the thing that it took a while for me to do, was to get past looking at how people look and appear and reacting to that, um I, I thought I had, I thought the three days at _____, I mean I came home from _____ just going, I have to go back through my files and write notes of apology to many, many people and many students that I've worked with and and I thought I had gotten past it, until I worked with students with Down Syndrome and that was the group that I said no way, I mean someone has to be, someone has to be

retarded and that's gonna have to be the group because they just look different and then I worked with some students with down syndrome and at that point it became real obvious that I had not shifted completely from what I would say to what I was actually doing, but that was the first thing, that we have to get past appearances, and the second things is that everybody communicates, even if you're not facilitating, that there are things that they're doing that are communicative that we're missing them, and that many people are seeing them communicate, and are missing it, you know, that there are glimpses that they're understanding in their day to day repertoire, we're just not seeing it because we are assuming that they do not know, they do not understand, therefore the fact that he laughed at the right time was an accident, nothing more, you know.

17. Yes, yes indeed, every day, every time. I'm surprised, I'm surprised by the depth of their insight, not everyone's but some of the kids. I'm surprised that some of the kids have the sense of humor that they have I'm surprised that some of them have this belief in God I'm surprised, uh, one of the young ladies I work with who's in high school now, her vocalizations which used to be completely useless, are now starting to match. If not the complexity, certainly the ideas um, of what she's spelling, um, and it always, it still surprises me when someone calls and says they validated again. You know, that, I just, it's sometimes easy to step back and say you know maybe there is no such thing as facilitation and then someone calls and says, you know she was spelling that such and such with a new person and she talked about something that happened in the past, and again it's true, and that always, not surprises me, but makes me just kind of take a deep breath again. Oh yeah, I remember what this is all about.

18. I, I think they can be, I also think they can be influenced. I'm working in a situation now where the the kid has facilitated fortunately for a couple of years, successfully, and validated for a couple of years successfully and now he's got a new facilitator and all of a sudden he can't spell, and all of a sudden he's using slang that we know, we know it's not him. I knew before I talked to him about, was he doing it he doesn't want to, I mean we're working on him to be more in charge, to delete what this other guy types for him, but the other guy is so cool, and the other kids at school like him, and so this kid is finding acceptance finally, so he's willing to let this other guy do his spelling. Now, in another couple of months we're gonna all be saying wait a minute, wait a minute, but yeah, I know they can be influenced, but I also know a lot of what they say can be very true, and I also know they can lie, or exaggerate, to get, especially the adolescent ones to get whatever it is people get when they exaggerate, and you know, I wouldn't say it's lying, but it's certainly stretching the truth.

19. I do, I think, I think that for people who are using facilitation, the people who are their facilitators need to have appropriate training. I think more than one person needs to be able to facilitate with a kid, adult, whatever, and should every day. It shouldn't just be through one person every day, every day, every day. Um for a lot of different reasons, one is the issue of influence. If we can match, if he's typing the same with this one as he is with that one, we've got some extra pieces of validation, but also because I don't tell all my deepest darkest secrets to one person, I tell one person about my family, I tell one person about my hopes and dreams, I tell one person...and so the more people that can talk intimately with people, the better, um, that's important. I also think we really, really, really need to struggle and figure out how to do independence. It can be done, it has been done, and we've just gotta convince everybody that's what we've got to be working on. There's few kids that I'm working with that, by golly, they should be independent by now, but the people that are working with them don't know how, or they switch jobs too often, or the kid is so delighted to be able to talk that losing any support means slowing down and getting, less communicative, I don't know, slower and sloppier and so, but they need to have time to work on it and that's one of my recommendations everywhere I go, is please set aside some time everyday to do, to work on independence, even if its even its simply talking the kid into, because if the kids not willing, then you're in trouble, and of course, as you start, the very first day, of a session with a kid, we should be talking from that moment soon you will be independent, soon meaning, I don't know how many years, or even if it's going to take years, but we certainly should be better at doing that.

20. Yes. (Why?) Because it's, for the students I've worked with they have validated so many times, and so many ways that, and the literature that is coming out now, I don't know if you're getting it, but the positive studies far outweigh the negative studies. And I just want to be there when what's-his-name up in Boston has to eat crow. That's going to be one of my best days.

22. Um, no, I do have some resources, that, I don't know what you're doing with your paper, but I do have some resources that you may find helpful, that I would be more than happy to lend ya. I just mailed the tape away, the independence tape, to _____. They're having a struggle once again, but I'd be happy to send that to you, if you'll just leave your address, she'll send it back, and then I'll send it over to you. I just haven't copied it, but it's, uh... Have you seen the Frontline, which of course caused all the...(I haven't seen it, but I've heard about it. I don't think I've seen it, which one is it?) Yeah, I have it. It's the one where Howard Shane, the Boston guy, said there's no such thing, and he gave the, they just kind of debunked it. (No, I haven't seen it). Yeah, I have that one too, I'd be glad to give you

that one, and then you could watch the independence one right after that. See, they had footage on Frontline, on Frontline, they had footage of people typing independently, and they didn't show it. They had the studies that were positive, and they didn't show it, it was, I think the week after Frontline was probably the worst one for some of the kids that facilitate, because if they hadn't facilitated for long, or they hadn't validated clearly enough uh, many of them lost, lost their facilitation. Their aides left the next day, I mean the school system pulled them. Uh parents stopped using it, it letter boards were put away, and communication was lost, and it was just devastating. I got so many calls that week of people just, even people who continued to do it but had doubts at that point, and it was just, of all the terrible things to do, these kids are so fragile at communication now, that that may be all it takes to say well, what's the point, it's not worth the effort. Um using facilitation is very difficult for kids and adults who use it, and and for people to be doubting it as they're doing it, I had a couple of kids just shut down and say no, I'm not doing it any more and they wouldn't even move their hand to the board, kids who had very willingly and spontaneously moved to the board wouldn't even look at the board from that point on. It was just, it was awful what had happened. Some of that has died down, and then they ran Frontline again, I mean a repeat of it, so I had to pack up all of this stuff and mail it out again to everybody. Um, but there's been the main studies up at Harvard that have, that have, for at least people with autism that have shown that the cognitive area of the brain is not different than ours. The part of the brain that's different is the part that controls movement, and the theory of a a movement disturbance that, that's been overlooked is certainly very plausible. Anne Donnellan has done some stuff, I'll show you her stuff too. It just makes so much sense. When Syracuse was doing it, they just had no idea why it would work, but she's got some theories that really make sense, especially if you start look at people who suffer from stroke and uh, the...Oliver Sacks has written a book, The Man Who Mistook His Wife for a Hat. And I mean, it was his wife, and if she talked he knew it was his wife, but if she didn't talk, he didn't recognize her, as even a person, I mean he was a music professor. He was a very brilliant man, but he had a problem with his brain. You see people with autism could have something along that line, not that particular thing, but, and we we misread it, we see it and say, ah, so he can't recognize familiar objects, put him in special ed. This one definitely has mental retardation, and you just look at it and think, oh, how wrong we could go you know, I mean we could convince kids that they're not very smart. There's a little girl in _____ I work with and she she has a lot of physical disabilities, and she has a disability that, traditionally, children who have it are very smart. It's a, it's a very long one, its a motor problem. And uh, and she I mean her teacher said to me there's just no one there, the lights are off, there's no one upstairs it's, this is a very severely, severely retarded child. She does nothing in response to anything and you know, I'm like well, okay, and I met her, and she was within an hour facilitating, at the elbow, okay, with I would guess forty people facilitating with her the first day. She did the Peabody Picture Vocabulary Test, um, and her IQ according to that, and I know, of course they don't correspond exactly, but it was above 140. I mean we were just, you know, and all of sudden everybody said well, we always knew, because she just pays attention when you talk about these things and she laughs at your jokes, and she you know, all of a sudden, people recognized that she was alert, and you know prior to facilitation, they were like... Now this little girl then had a bunch of seizures and a lot more trouble motorically, and she's no longer facilitating, but, but everybody still knows that she's smart, and they talk to her, and they include her, and she goes on family trips where she never did and she goes out to church where she never did, and she just looks like a different kid. And it isn't because she's facilitating everyday saying I'm smart, I'm smart, it's just that now we know, so we treat her differently, and I think, you know when you were talking about the beliefs, one of the things that we have to do is, we have to treat everybody like, they're people and, and, I mean not that they're smart, but if you treat them with respect and talk to them like they're people, I think you end up with a different outcome, than what we see now, we certainly see what happens when we treat them differently.

TABLES 1 - 8

TABLE 1

Supporting Statements Of Recognition of Facilitator Influence Theme

Subjects	Statements
#1	Um, I do believe people can influence...but I would be very naive if I thought somewhere along the way someone had not moved his hand because... it's very easy to get real enthusiastic and kind of anticipate what you think someone's going to say and kind of subconsciously move it.
	...[the students] need to learn that they need to let [the facilitator] know that [the facilitator] might be leading them, or that [the facilitator] might be influencing them
	...a best practice is to teach the speaker who is being facilitated to hit a block or to say "no" or some way to indicate that you might be either misinterpreting or leading them, influencing them, what they have to say.
	I think it's important for people to get proper training and to understand that they can lead and they can interpret.
	...I think it's real important for people using facilitated communication who are the facilitators to be aware that they can influence people...
	Um, I think you always need to be aware that you can influence people.
	...I kind of probably give him a little more backwards resistance when I think I know what's coming next, so that I make sure I'm not going to be influencing his next letter choice.
	I think that there are people that, with all the best intentions in the world, say what they think the person wants to say, and move their hand around.
#2	...I have taken several one or two day local workshops in order to learn how not to influence.

TABLE 1 continued

Subjects	Statements
#3	...but the hand over hand and going straight down in a vertical movement to a board or a letter really leaves a lot open... And then you had facilitators that were leading these people, and it may even be almost semi-subconscious, but they're doing it.
#4	And I think with everyone, there's always a question as to who is doing the communicating, whether it's actually the person.
#5	...I ask people, "Was that your word or mine" if I think maybe I didn't allow their hand to move... But I think you have to go into this process explaining that, "I'm not sure, I may get in the way of what you're trying to say, or it may not come out like you want or you know, I might move your hand... ...one of the portable ones I use has a couple of things on it that the person just has to point up there that says "You moved my hand." I want to be the first to know, not the last to know if I moved your hand, or if that's not what I meant, or you know, don't understand. ...I just want to be sure if I'm moving somebody's hand I thought, well, I mean, I feel awful if somebody points there, but in a way I feel good because I want to know.
#6	...people don't always believe in it, it's easy to be influenced, so you're really not getting your message across, I mean, it's filled with a lot of problems... ...I also think they can be influenced.

TABLE 2
Supporting Statements Of Support Network Theme

Subjects	Statements
#1	...I was the only person in Richmond who had tried it or was working on it, so I didn't have any support. . .it would have been sufficient had I had a support group and a network around me that I could problem solve, and talk about things with... I didn't really have anybody helping me so I wasn't doing it as well.
#2	...the whole group that I got trained with were people from all over the United States, then we all came back to our communities and we didn't really have a support system here. We still don't have a support system, so it's hard to sustain it.
#3	None.
#4	None.
#5	What I felt was needed was having support. I had enough other people...in the area, who were doing the method, and we formed a support group, and we met for a couple of years, we met about once a month, and we talked about what's working and what's not working...whatever, and that was helpful, so I wasn't on my own doing this method, that's real key. When you have someone use any method that's new to them or that they use in isolation from anyone else, and they have no support, no one's technical support, no one can help them improve... I mean, you need a team of people, and you need that administrator's support, because they need it so much... I think doing it in isolation is something you wouldn't want to do... ...I think some people have fairly bravely, or maybe just fairly ignorantly done it, in isolation without the support of other people, and ended up in real tragedies. Systems shouldn't let that happen, they should support people, and what happens is systems have shut people down, and that's a big mistake.
#6	...if you were gonna do it with your classroom, and you were only gonna see your group of kids you probably would...need on going support

Table 3

Supporting Statements For Application To Other Populations Theme

Subjects	Statements
#1	Well, certainly with people with autism, and people with CP, it helps to provide a staying touch for someone that has a tremor. I think that they have used it successfully, although I have not tried it, with some people with Down Syndrome, who have some speech, quality of speech that's hard to understand. I think it would be neat to try it with people who have had strokes. I think that they should try it with people who have had strokes...
#2	I have used this with some individuals with cerebral palsy, individuals who are mentally retarded, people who have oral dyspraxia, or oral dysphasia. I've always been interested in, but haven't had the opportunity to use it with people who have had strokes.
#3	I would think it would work with cerebral palsy.
#4	...I think it would be valuable for anyone that had a problem with speech.
#5	...I guess the people I've had success with have been people...with autism who speak or don't speak, people with severe and profound labels, or moderate who may speak or may not speak at all, people with pervasive developmental disorder...and Down Syndrome. ...and I don't think it's only for people with autism...
#6	I think any child who cannot communicate verbally or effectively verbally, that anything, any kind of communication, any kind of augmentative communication system that will help them communicate more effectively should be tried.

Table 4

Supporting Statements For Multiple Facilitators Per Student Theme

Subjects	Statements
#1	...I think one of the best practices that you can do is train a lot of facilitators. Okay, one of the things is, I think it's really important to train several people around one individual... ...it's really good to brainstorm and have a whole group of people...for the person that's being facilitated, so they don't depend on one person so much.
#2	...and that would make it difficult for people to communicate with many varied individuals, which of course is what we want. We want kids to be able to communicate with the kids in their classes and not necessarily have an adult around all the time.
#3	None.
#4	None.
#5	None.
#6	I think more than one person needs to be able to facilitate with a kid, adult, whatever, and should every day. It shouldn't just be through one person every day, every day, every day. ...the more people that can talk intimately with people the better...

Table 5

Supporting Statements For Dissatisfaction With Formal Training Theme

Subjects	Statements
#1	...I went through a lot of training, and for the first thirteen months I was doing it with Matthew I don't think I had enough training.
#2	...there needs to be some more kind of organized training, preparation, for teachers and aides, and, well, professionals and paraprofessionals who work with individuals with developmental disabilities... ...but yes, training is a very big problem...
#3	None.
#4	None.
#5	None.
#6	The training was probably not sufficient, if someone were just gonna do the six hours, and then observe and then go back to the classroom.

TABLE 6

Interrater Reliability Between Investigator and Expert #1

Themes	Percentage of Reliability
A Dissatisfaction With Formal Training	100%
B Application To Other Populations	100%
C Recognition Of Facilitator Influence	100%
D Need For A Support Network	100%
E Need For Multiple Facilitators Per Student	100%
Overall	100%

TABLE 7

Interrater Reliability Between Investigator and Expert #2

Themes	Percentage of Reliability
A Dissatisfaction With Formal Training	100%
B Application To Other Populations	91%
C Recognition Of Facilitator Influence	100%
D Need For A Support Network	93%
E Need For Multiple Facilitators Per Student	100%
Overall	98%

TABLE 8

Interrater Reliability Between Expert #1 and Expert #2

Themes	Percentage of Reliability
A Dissatisfaction With Formal Training	100%
B Application To Other Populations	91%
C Recognition Of Facilitator Influence	100%
D Need For A Support Network	93%
E Need For Multiple Facilitators Per Student	100%
Overall	98%