

**THE EXPERIENCES OF PARENTS AND PROFESSIONALS
WITH THE TECHNIQUE OF FACILITATED COMMUNICATION**

by

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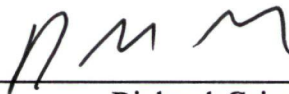
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "The Experiences of Parents and Professionals with the Technique of Facilitated Communication" submitted by Colleen Trapp in partial fulfilment of the requirements for the degree of Master of Social Work.



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ABSTRACT

Facilitated communication is a technique whereby an individual communicates by pointing to symbols, letters, or words with the physical support of another person. This technique has been introduced to the autistic population in order to bypass their severe communication difficulties.

This study was comprised of eleven parents and sixteen professionals who were involved with the Society for the Treatment of Autism in Calgary, Alberta. Separate questionnaires, designed to yield information on the experiences of the children, parents and professionals using the technique, were distributed.

All the children in this study appeared to experience some degree of success. Parents and professionals were basically optimistic about facilitated communication and what it could mean to the future of children diagnosed with autism. Professionals were more confident; however, both groups tempered their optimism with caution regarding total acceptance of the technique.

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CHAPTER 1

INTRODUCTION

This chapter focuses on research problem, its definitions, as well as its history. Also discussed is the significance of this topic, not only to social work practice, but also in regard to theory and policy.

RESEARCH PROBLEM

The proposed topic of study is facilitated communication. Facilitated communication is a technique that, according to some professionals, provides a glimpse of what goes on in the minds of children diagnosed as autistic that other procedures have failed to deliver. It appears to assist some children with autism in communication.

Definition of Autism

Autism is a life-long disability which occurs in approximately 4.5 per 10,000 live births (Charlop, Schreibman & Kurtz, 1991; Rosen, 1989). It is usually diagnosed before 3 years of age in children who appeared normal at birth, occurring 3-4 times more frequently in males (Bristol, 1985; Charlop et al., 1991; Rosen, 1989). Autism is characterized by profound deficits in language acquisition and use, severely impaired social development, stereotypical and bizarre behaviours, and an exaggerated or oblivious response to the environment (Kostanareas, 1990). It is also

characterized by abnormal posture and motor behaviour (Society for the Treatment of Autism [STA], 1991).

Definition of Facilitated Communication

"Facilitated communication is a technique whereby an individual communicates with the physical and emotional support of another individual known as a facilitator, by pointing to objects, pictures or letters. The degree of physical support given varies depending on the needs of the individual, but it most commonly involves slowing the person's movements down by providing counter resistance and pulling his hand back after each response" (STA, 1991). Essentially at first it involves hand-over-hand, or hand-on-forearm support of the students who are communicating. Sometimes it is necessary to isolate the index finger. Over time it is anticipated that this kind of support can be faded back to a touch on the shoulder or to total independent communication (Biklen & Schubert, 1991; Biklen, Morton, Saha, Duncan, Gold, Hardardottir, Karna, O'Connor & Rao, 1991).

Facilitated communication is not the physical support involved, nor is it a physical prompt. It is not a physical guide, a demonstration of how to type, or an academic exercise. Most importantly, it is not the facilitator manipulating the choice (STA, 1991).

Background to Problem

In 1943, Leo Kanner described a group of 11 children whose symptoms appeared to differ from those exhibited by children who suffered from other

childhood disorders. He used the term "infantile autism" to describe this phenomenon (Charlop et al., 1991; Ritvo, 1976; Jenson & Young, 1985). In subsequent years, as autism received more attention, other clinicians began to expand the term to include other disorders, such as "childhood schizophrenia" (Lauretta Bender, 1947), and "symbiotic psychosis" (Margaret Mahler, 1952) (Ritvo, 1976; Sauna, 1983). According to these clinicians, autism was caused by familial pathology. Parents were thought to be cold and often referred to as "refridgerator parents", causing children to withdraw to their own worlds in order to protect themselves (Bristol, 1985). This belief was based on psychodynamic theory (Schreibmann, 1988).

Although Kanner's original checklist used for diagnosing autism has appeared to have survived the test of time, theories surrounding the exact nature and cause of autism have changed. Autism did not appear in the Diagnostic and Statistical Manual of Mental Disorders (DSM III) as a distinct entity until 1980 (Jenson et al., 1985). Separating children who are actually autistic from those who display autistic-like behaviours continues to be a challenge (Jenson et al., 1985; Sauna, 1987).

Although the majority of clinicians now agree that autism is not psychogenically caused, there is still dispute as to the exact cause of the disorder (Schreibmann, 1988). Today most see autism as being caused by genetic and biological factors. Clinicians are now pursuing neurochemical and neurological studies in order to determine factors involved in the development of autism. However, there is wide variation, and nothing definite has been substantiated (Schreibman, 1988). Treatment of children with autism has been a goal since autism

was first discovered. Treatments have ranged from psychoanalysis to behaviour modification. Drug therapy has also been popular in order to control maladaptive behaviours, and has been thought to be effective in curtailing biochemical aberrations (Schreibman, 1988).

It appears that whatever the cause of autism, a cure to this syndrome is not imminent. Unfortunately, it also seems likely that in order for us to be able to intervene and help families and children function more appropriately, there first needs to be more evidence regarding the development and manifestation of the autistic syndrome.

In 1990, Douglas Biklen introduced North America to a "new" technique in helping children with autism communicate, called "facilitated communication." Biklen was introduced to this technique at the DEAL (Dignity through Education and Language) Communication Centre in Melbourne, Australia by Rosemary Crossley. She began using the technique in 1977 with cerebral palsy individuals (Crossley & MacDonald, 1980; Crossley, 1992; Crossley, 1992; Biklen, 1990; Biklen & Schubert, 1991). In 1991, facilitated communication was introduced by the Geneva Centre in Toronto, following consultation with Biklen. Some months later, facilitated communication was introduced in Calgary by the Society for the Treatment of Autism after speech pathologist, Shelly Vandervelde, visited Crossley at DEAL (Vandervelde, 1992).

Although the technique of facilitated communication has been viewed as a new concept in the autism field, the mechanics of it are not. There have been in the

past a number of references to people with autism being able to communicate by typing with the aid of a facilitator (Schawlow & Schawlow, 1985; Eastham, 1985, 1990, as cited by Biklen, Morton, Gold, Berrigan & Swaminathan, 1992). Unfortunately these incidences were treated like isolated events and the individuals were thought to be types of "savants." Oppenheim (1974) wrote that children with autism could learn to write if they received physical support. It was her position that children with autism encounter poor motor control, and require physical support in order to write. Sometimes all they required was a touch of the hand. It was her contention that this support could be faded out to just a touch, or to total independence (Oppenheim, 1974).

In the early 1960's several children diagnosed as autistic were able to demonstrate typing abilities on an electronic typewriter. Although phrases children typed were mainly echolalic in nature, they did display an ability to spell. Some advanced in their ability to read, and others began to speak. It is important to note that much of this typing was done independently (Goodwin & Goodwin, 1969).

IMPORTANCE TO PRACTICE

The literature suggests that with facilitated communication a high percentage of children with autism, previously assessed as extremely low functioning and severely intellectually impaired, are able to communicate in ordinary language, often showing surprising literacy skills. Children are able to express feelings, values, and abstract thought; they reveal none of the abnormal language structure common to autism, such as echolalia, and pronoun reversal (Remington-Gurney & Crossley, 1990;

Crossley, 1992; Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992). Vandervelde (1992) reports a 90% success rate in students working with Crossley. In Syracuse, Biklen reports a near perfect success rate (Biklen & Schubert, 1991; Biklen et al., 1991); the Toronto Geneva Centre reports a 90% success rate (Vandervelde, 1992).

It is important to note that these agencies may have varying definitions of success. For example, some may see success as a child being able to type one-word answers, as with the Geneva Centre (Vandervelde, 1992). Biklen & Schubert (1991) view success as a child being able to respond accurately to questions, either by sentences, words, indicating "yes" or "no," or pointing to pictures. As well, the children who are selected to communicate through facilitated communication in these programs may be somehow different from those who haven't had a chance to try. In the Biklen & Schubert (1991) study, none of the students selected had sophisticated or socially useful verbal ability.

An important aspect is that not everyone is successful as facilitators, and some children will not be able to perform with different facilitators. The level of support a facilitator provides differs from child to child, and even from facilitator to facilitator. Therefore, success is not consistent over different situations and parties (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992).

Theoretical Significance

Facilitated communication does not purport to be a cure for autism. It does, however, call into question previous theories surrounding the autistic syndrome.

According to the Geneva Centre, the use of facilitated communication will have an impact on the lives of people with autism, and those who interact with them. "More specifically, the impact will be felt in our perceptions of individuals with a diagnosis of autism and will provide new challenges and insights into our current understanding of the disorder and its treatment" (Geneva Centre, [GC], 1990).

In order to accept facilitated communication practitioners must be willing to rethink hypotheses surrounding the theory of autism being a social-cognitive-language disorder. At this time there is controversy among autism experts as to whether or not facilitated communication is valid. Some believe the facilitator is manipulating the communicator. As facilitated communication gains more acceptance, it is hoped that further neurological studies will be done in order to gain more understanding as to why facilitated communication works, and to shed more light on the development of the autistic syndrome.

Policy Significance

Facilitated communication appears to expand opportunities for many children with autism, but only to the extent that professionals allow these opportunities to exist. It may also increase the integration of children diagnosed as autistic into mainstream schools. Allowances for the use of facilitated communication in the classroom may enable children with autism to participate in classes in ways they have never been able to before, both academically and socially. The normalization of many of these children through facilitated communication may increase present and future independence.

In the past few years advocates for the handicapped have made a move towards equality and highlighting people's abilities rather than their disabilities. The literature has reflected a shift in terms such as "handicapped" versus "challenged", and "train" versus "facilitate." "This philosophical revisionism has matched well our natural, clinical predispositions toward a combination of optimism and hope" (McLean, 1992, p. 26). Facilitated communication, as an augmentative approach to communication for people "challenged" with autism, aligns itself with this philosophical approach. This in itself holds a basis for subjectivity and bias in analysing the technique (McLean, 1992).

Social Work Significance

Facilitated communication may have an impact on parents of children with autism. Parents may be experiencing conflicting emotions and stress. Some parents may have a past experience with raised expectations and hopes for improved functioning of their children, only to be disappointed. Facilitated communication may be viewed as another such "miracle." Social workers can play an important role in helping families come to terms with what facilitated communication may mean to them. Parents may also feel guilty, realizing that their child has had the capacity to communicate all along.

Professionals working with clients with autism may find themselves being more sensitive to their clients. In this way professionals will make more of an effort to address their clients at their age level, not discuss clients in front of them, and relay

a sense of hope and respect which may have been obscured in the past by the very challenging behaviours which characterize the autistic syndrome.

For all these reasons this researcher believes facilitated communication to be a very important area of study.

SUMMARY

This chapter focused on definitions and the history of the research problem. Further research is needed in order to realize the full impact facilitated communication will have on the autistic population. Facilitated communication is also likely to have an impact on policy, theory, and social work practice with the autistic population.

CHAPTER 2

LITERATURE REVIEW

INTRODUCTION

This chapter reviews the literature relevant to the research problem. Areas covered include characteristics of children with autism, hypotheses surrounding autism, qualitative and quantitative studies of facilitated communication, the mechanics of facilitated communication, and critiques of facilitated communication. Also discussed are communication and parental stress, educational issues, and a conceptual framework.

CHARACTERISTICS OF CHILDREN WITH AUTISM

As mentioned in Chapter 1, children with autism have a number of characteristics which greatly impair their overall development. In fact, many children with severe autism may appear to have global functional delays, meaning social, communication, cognitive and language problems. Specific behaviours and characteristics described may be present in other forms of pervasive developmental disorders and children who have autistic-like tendencies, but who are not truly autistic.

Social Behaviour

Children with autism manifest profound deficits in social behaviour. For many of them, interest in other people are merely to use them as tools, such as using a

person's hand to open the door (STA, 1992). Some rarely interact with others, or even develop affection for other people, and avoid physical contact (Charlop et al., 1991; Jenson et al., 1985; Ornitz & Ritvo, 1976). However, some children with autism have been known to be quite cuddly, but only on their terms, i.e., they have to be the ones who initiate contact (STA, 1992). Children with autism exhibit poor eye contact, and often display indifferent reactions to their environment. They also display inappropriate laughter and affect (Charlop et al., 1991; Jenson et al., 1985; Ornitz & Ritvo, 1976).

Perception Disturbances

Perception disturbances in children diagnosed as autistic alter their ability to interact with their environment. They basically cannot properly modulate external sensory input, resulting in alternating hypo and hypersensitive states (Ornitz & Ritvo, 1976).

Children who are hyporesponsive generally are not reacting to either verbal commands, sounds, or even visual cues. In this sense children are totally unaware of loud noises or even the entrance of people into their environment. Children will not respond to aversive tactile stimuli; therefore they will feel no pain if they fall or cut themselves (Ornitz & Ritvo, 1976).

On the other hand, children in a hypersensitive mode will have exaggerated reactions to outside stimuli. Children may be distracted by a seemingly innocuous sound. They may be visually hypersensitive and be totally absorbed with the grain in a piece of wood. Additionally they may become tactically absorbed in textures.

Reactions can be quite negative. Sudden changes in illumination or sudden confrontations with people may elicit extremely fearful responses (Ornitz & Ritvo, 1976).

Language Development

Children with autism are significantly impaired when it comes to language development. Many are totally non-verbal. Other common dysfunctions include echolalia, pronoun reversals (using 'you' for 'I'), and difficulty in discrimination of polar language concepts ('yes' and 'no') (Jenson et al., 1985; Ornitz & Ritvo, 1976). According to Rutter (1978), language development appears to be deviant from the onset (Jenson et al., 1985). In a number of studies (Eisenberg, 1956; Rutter et al., 1967; Mittler, Gillies & Jukes, 1966; DeMyer et al., 1973), it has been shown that about one half of children with autism fail to acquire speech by adolescence (Mesibov, 1983). Those who do tend to have irregularities in their patterns, such as flat affect, staccato, and monotone speech (Mesibov, 1983; Jenson et al., 1985; Charlop et al., 1991).

Stereotypical Behaviours and A Need for Sameness

Common characteristics of children with autism include arm flapping, whirling, head banging, rocking, and rhythmic manipulation of objects (Ornitz & Ritvo, 1976; Jenson et al., 1985). They also tend to exhibit unusual body or hand postures. For example, children may "toe-walk," rather than use their whole foot. Children with autism also tend to become fixated on certain objects or activities and will spend an

unusual amount of time engaging in activities or form bizarre attachments to objects. Finally, they tend to become upset if rituals become interrupted, or if things in their environment change. They also spend quite some time lining up objects (STA, 1992).

Self-injury and Aggression

Self-injurious behaviours include head-banging, eye gouging, face hitting, biting, and mouthing objects. (Jenson et al., 1985). Other-directed aggression can also be quite common. Children may frequently cry, scream, hit, bite, kick, or throw objects (Charlop et al., 1991).

HYPOTHESES SURROUNDING THE AUTISTIC SYNDROME

Autism as a Social-Cognitive-Language Disorder

It has been accepted in the past that 80% of children with autism are mentally challenged to varying degrees (Moroz, 1989; Ritvo & Freeman, 1977; Charlop et al., 1991; Schreibman, 1988). Mirenda and Schuler (1988) report that children with autism have "severe social-cognitive limitations" (Mirenda & Schuler, 1988, p. 25). According to Paul (1987), children with autism do not understand what the purpose of speech is and that their receptive language is poor. They appear to only use language to request or protest (Paul, 1987).

A repeated theme in the literature is the child's lack of cognition and a failure to understand all the intricacies of human interaction. Some theorists hypothesize that the echoed speech, especially delayed echolalia, common to autism are actually

pre-intentional attempts at communication (Prizant, 1983, as cited by Biklen & Schubert, 1991). Schopler, Reichler, and Lansing (1980) view echolalia as simple parroting, and that children do not understand the content (Biklen & Schubert, 1991; Biklen et al., 1991). It is believed that because children with autism cannot understand or make sense of social processes, they are equally unable to grasp the concept of purposeful language (Paul, 1987). Baltaxe and Simmons (1977) believe that although children with autism may be able to use echoes towards functional communication, this is very limited (Biklen et al., 1992). It is also believed that they have great difficulty understanding abstract thought (Rick & Wing, 1975, as cited by Mesibov, 1983).

Some children diagnosed as autistic have been labelled "hyperlexic," meaning their word recognition outdistances presumed intellectual capabilities. Others have been seen as "hypergraphia," meaning their writing abilities exceed their supposed intellect (Whitehouse & Harris, 1984, as cited by Biklen et al., 1992). These children generally have demonstrated a preoccupation with books that is almost compulsive. They spend much of their time decoding signs, television slogans, and telephone books. However, it has been thought that these children do not comprehend the meaning of what they're reading. It has further been contended that the tendency to believe these children are demonstrating intellectual ability has led to inappropriate placement in classrooms (Whitehouse & Harris, 1984, as cited by Biklen et al., 1992).

It has been suggested that children with autism even process stimuli differently than children who do not have autism. Rather than storing and processing bits of information, children with autism store chunks of language, often referred to as "gestalt processing." This would make it extremely difficult for them to adequately analyse the intricacies of social interaction (Prizant & Schuler, 1987). The phenomenon of echolalia may be explained through gestalt processing. This may also explain why many children with autism do much better at visio-spatial tasks, such as puzzles and arithmetic. These are nontransient stimuli, which are much more compatible to gestalt processing (Prizant & Schuler, 1987).

It has been suggested that some of the maladaptive behaviours children with autism display are attempts on their part to communicate (Carr & Durand, 1987). It has also been hypothesized that aggressive behaviour towards self or others is a protest to demands placed on children by their caregivers (Mesibov, 1983). For example, Temple Grandin, a recovered autistic, stated that screaming was often the only way she knew to express unhappiness (Grandin & Scariano, 1989).

Sensory Disturbances

There have been several hypotheses surrounding the obvious sensory disturbances children with autism exhibit. Lovaas, Schreibman, Koegal & Rehm (1971) view perception disturbances as "stimulus overselectivity," where children respond "only to part of a relevant cue, or even to a minor, often irrelevant feature of the environment, without learning about other portions of the environment" (Jenson et al., 1985, p.178; Charlop et al., 1991, p.259).

Not all children with autism display stimulus overselectivity. It has been hypothesized that it is more of a function of developmental level, rather than autism. Wilhelm and Lovaas (1976) discovered that children with low IQ's responded less to stimuli than their counterparts with higher IQ's. It is believed that stimulus overselectivity is documented so frequently in children with autism because many are low functioning. It is further believed that this dysfunction is part of the reason children diagnosed as autistic have such difficulties in learning new discriminations, generalization of acquired behaviour, social recognition, transfer from prompt stimuli, and observational learning (Schreibman, 1988).

Dawson and Lewy (1989) propose that children with autism may have a lower optimal level of stimuli than children who do not have autism. In this sense they can only deal with a limited level of stimuli without being overloaded and displaying an aversive response (Dawson & Lewy, 1989).

The Role of Genetics

Researchers have yet to find a specific gene marker for autism. It has been documented that autism is more prevalent in males. This in itself implies some sort of genetic component (STA, 1992). The prevalence of autism in siblings of children with autism is higher, and even higher in monozygote twins (Rutter, 1967; Silliman, Campbell, & Mitchell, 1989). There also appears to be an association between autism and other handicaps such as fragile X syndrome, cognitive and language disabilities, and affective disorders (Piven et al., 1990). Other disorders which have been identified with autism are phenylketonuria (Lowe, Tanaka, Seashore, Young,

& Cohen, 1980), and congenital rubella (Chess, Corn, & Fernandez, 1971) (Silliman et al., 1989). Current neurological studies to be presented later in this review also suggest a strong genetic component.

Neurological Disorder

In the past, neurological studies and hypotheses led researchers to believe that the cognitive and language centres of the brain were damaged with autism, primarily the left hemisphere (Blackstock, 1978; Dawson, 1979; Dawson, Warrenburg, & Fuller, 1982; Prior & Bradshaw, 1979; Tanguay, 1976, as cited by Schreibman, 1988). This does not, however, explain why the right hemisphere does not compensate for the left, which has been evidenced in children with damaged left hemispheres up to 6 years of age. Damage to the left hemisphere also does not explain "autism," as many children may have cognitive deficits, but are not autistic (Schreibman, 1988).

Maurer and Damasio (1982) believe that children with autism require physical support to initiate, follow through with, and stop some movements. They see these problems as falling under the conditions of "akinesia (absence or poverty of movement or delay in initiation of movement) and bradykinesia (slowness rather than absence of movement)." Bradykinesia includes delay in initiating or stopping movement, delay in changing a motor pattern, and a quickness to tire during prolonged tasks (Adams & Victor, 1977 as cited by Maurer & Damasio; Hallet & Koshbin, 1980, as cited by Maurer & Damasio; Donnellan, Sabin, & Majure, 1992). Through clinical inference, Maurer and Damasio hypothesize that disturbances in mobility, communication, and attention and perception are the result of dysfunctions

in those areas of the brain that make up the limbic system (Maurer & Damasio, 1982). The limbic system is responsible for emotional experience and expression, and can modify the way a person acts; and it produces such feelings as fear, anger, pleasure, and sorrow (Hole Jr. & Koos, 1991). Studies have suggested that children with autism demonstrate impaired social expression when compared with normal and intellectually impaired children (Mundy & Sigman, 1989; Dawson & Lewy, 1989). Other parts of the limbic system, such as the basal ganglia and the thalamus, control various muscular activities and act as a central relay station for sensory impulses. They are also responsible for channelling impulses received to appropriate regions of the cortex (Hole Jr. & Koos, 1991). Children with autism generally have sensory disturbances.

In a recent study by Courchesne involving the examination of autopsies and neuroimaging data, it was discovered that there was substantial cell loss in the cerebellum in all autopsies and most neuroimaging studies involving people with autism. The latter studies are much less sensitive than autopsy studies, which would explain lower instances (9 times out of 12 as opposed to all autopsy cases) of detected cell loss (Courchesne, 1991). It would appear from these studies that hypoplasia of the cerebellum likely occurred in utero at the end of the first trimester, as there is no evidence of atrophy or deterioration, which would be indicative of hypoplasia occurring after full development (Courchesne, 1991). This suggests some genetic involvement.

The implications of this discovery are great. The cerebellum projects to those centres involved in motor initiation. This implicates the limbic system, the reticular activating system, neurotransmitters, and the frontal lobe (Courchesne, 1991). Regions in the frontal lobe are responsible for language tasks. Cerebellar lesions in mammals tend to disturb motivated behaviours and reduce social interactions. PET scans suggest that damage to the cerebellum may "impair coordination at attentional deployment during active behaviour" (Courchesne, 1991, p. 788). The cerebellum is viewed as the center for controlling and coordinating muscles, and it maintains posture. The eyes and ears are also involved. Damage to the cerebellum is likely to result in inaccurate movements of voluntary muscles (Hole Jr. & Koos, 1991). All of these tasks are seen as abnormal in children with autism. It is important to note that Courchesne states that the cerebellum is "an unlikely site of damage for a developmental disorder of higher cognition such as autism" (Courchesne, 1991, p. 788).

Autism as a Movement Disorder

The above paragraph leaves one to consider whether autism is a movement disorder, rather than a cognitive-social-language disorder. Facilitated communication certainly challenges the latter hypothesis. Biklen (1990) and Crossley (1988) suggest that since children with autism have many coordination problems, complex movements are extremely difficult (Biklen & Schubert, 1991; Biklen et al., 1992). Talking involves many muscles and the timing and coordination of these muscles are essential. The cerebellum is responsible for the regulation and coordination of

movement and if it is underdeveloped, it seems reasonable to propose that speech would be a problem. On the other hand, typing with one isolated finger is a far less complex movement and each letter typed involves essentially the same movement. Perseveration and "freezing" are often functions of children having problems negotiating movement (GC, 1991). Facilitators simply help children control and initiate purposeful movement (Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992; Crossley, 1992).

The stereotyped behaviours and echolalia common to the autistic syndrome are viewed as automatic behaviours which are triggered by objects, persons, words, and events in the environment. In fact, many children with autism have reported through facilitated communication that they do not want to behave as such, but they cannot help it (Vandervelde, 1992). Similarly when some children open their mouths to speak it may be that what comes out has nothing to do with their communicative intent (GC, 1991). While typing accurate responses to questions children have been reported to be signing or saying inaccurate answers, which are either echolalic or perseverations (Vandervelde, 1992; Biklen et al., 1991). Children with autism may also respond poorly to transitions because those few cues they have come to depend on for their automatic behaviours change (Vandervelde, 1992).

Some behavioural reactions could be the result of inner stimuli and thoughts. Children may react seemingly out of context because they remember something upsetting which happened months ago (GC, 1991).

Temple Grandin (1989) reported that she had a problem as a youngster channelling sensory stimuli. She reported often being "over-loaded" with noise in her head and that it was very painful. Fixating, or engaging in the stereotypical behaviours soothed her (Grandin & Scariano, 1989). Many verbal children with autism have reported not knowing which sensory modality they are experiencing (Vandervelde, 1992). As mentioned earlier, the eyes and ears are implicated in cerebellum functioning. If the cerebellum is underdeveloped then it stands to reason the coordination of incoming stimuli from the eyes and ears may be dysfunctional.

The Apraxia Hypothesis

Apraxia has been hypothesized to be a problem for children with autism (Biklen et al., 1992; Biklen, 1990; Oppenheim, 1974). Apraxia refers to serious disturbances in executing a sequence of voluntary movement (Luria, 1966, as cited by Gleitman, 1981).

Apraxia has been identified as a possible reason why facilitated communication has been successful where other techniques have failed or been less successful. Furthermore, apraxia does not necessarily imply cognitive deficits. Children with autism have difficulty producing multiple words or complex statements, rather than single words or familiar multiple words. Slowing down the communicators movements during facilitated communication also reduces the amount of echoes (Biklen et al., 1992). This is consistent with the notions of apraxia "where complex movements are more difficult than single motor tasks" (Kelso & Tuller, 1981, as cited by Biklen et al., p. 25, 1992). People with apraxia typically are able to utter

predictive greetings, advertising jingles, and songs with considerable ease, but cannot produce nonautomatic speech. This has been clearly evidenced in people suffering from autism (Biklen et al., 1992).

Apraxia was also described by Temple Grandin who stated that she could understand what was being said to her, but was unable to answer (Grandin & Scariano, 1986). Biklen (1990) hypothesizes that children with autism are able to express phrases that have already been "introduced aurally; the more advanced version of the speech output device can select segments of phrases and join them with others, though it generally lacks the program to "output" verb tense and pronouns correctly. With facilitation, the person can bypass his or her problem of verbal expression and type natural language" (Biklen, 1990, p. 303).

STUDIES ON FACILITATED COMMUNICATION

Qualitative Studies

Studies in the area of facilitated communication in the past have by and large been qualitative in nature. These studies have described the content of students' communication through facilitated communication. Crossley (1988) reported that of 34 students diagnosed as autistic, or intellectually impaired with autistic tendencies, 23 communicated with sentences, 2 with single words and one with yes/no responses. Three participants did not show progress, and 5 were lost to follow-up (Biklen & Schubert, 1991; Biklen et al., 1991). In a more recent article by Crossley & Remington-Gurney (1992) they report that between the start of 1986 and the end of

1990, out of 117 individuals diagnosed as autistic and intellectually impaired, 91 showed spelling skills adequate for communication during their assessment. Prior to their referral to DEAL, only 12 demonstrated literacy skills (Crossley & Remington-Gurney, 1992). Biklen's first article on the subject in 1990 relayed his experiences at DEAL when he visited Rosemary Crossley to see what facilitated communication was all about. All 21 subjects were able to read and type single words or sentences (Biklen, 1990; Biklen, 1992).

The following year, Biklen and Schubert conducted a study on another 21 children in Biklen's program in Syracuse, using qualitative methods. All demonstrated literacy skills, and 18 were able to produce sentences. All these children were quite limited in their ability to communicate by means other than facilitated communication. None had socially useful language (Biklen & Schubert, 1991). Data collection included observations of students in the classroom while not using facilitated communication; observations of students using facilitated communication with a facilitator in the classroom and/or in speech therapy sessions; and videotaping of students using facilitated communication in the classroom and speech therapy sessions (Biklen & Schubert, 1991).

Eleven different researchers participated as observers in order to ensure validity. Researchers also received collateral data from parents, teachers, speech therapists, and teaching assistants (Biklen & Schubert, 1991). Analyses of the data were conducted within traditional qualitative research methods and grounded theory

(Becker, 1969; Bogdan & Biklen, 1982; Glaser & Strauss, 1967; Hammersley & Atkinson, 1983; Mishler, 1990) (Biklen & Schubert, 1991; Biklen, 1992).

A second study was conducted by Biklen and colleagues at Syracuse University involving 22 students, using the same qualitative methods as in the previous study. Of the 22 students, 19 produced sentences, although two children only produced simple sentences. "Each of these students demonstrated unexpected cognitive and receptive abilities, including excellent awareness of their environment and interest in other people, such as fellow students, their teachers, and parents" (Biklen et al., pp. 175-176, 1991).

A recent study was conducted in order to describe and consider implications for children with autism involved with facilitated communication. Areas of focus included processes perspective facilitators go through in order to help communicators get started, strategies involved in helping students communicate as well as moving them from structured communication to unstructured communication, and unobtrusive measures used to verify that the students were communicating their own thoughts (Biklen et al., 1992).

Forty-three students, aged 3 to 26 years participated in the study. All had classical autistic symptoms and exhibited ineffectual spoken communication. Before using facilitated communication none of the participants could do academic work at or near their grade level and were considered low functioning. This study was conducted using qualitative research methods mentioned in previous Biklen studies

and took 16 months to complete (Biklen et al., 1992). Results of this study are included in the outline of conditions required below.

CONDITIONS REQUIRED FOR FACILITATED COMMUNICATION

Communication Content

This condition involves the process of moving from structured practice work to unstructured, open-ended practice work. Biklen (1992) has not observed a student being able to type conversational language without first being introduced to facilitated communication through structured practice work. Structured work consists of fill-in-the-blank exercises, yes/no responses, multiple choice, simple math problems, asking if students could spell their name, object labelling, and sentence completion. These exercises involve predictable responses and have been labelled "successful choices" (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992). Often following these sessions students are nevertheless invited to say anything that is on their minds.

The time taken to move from structured work to unstructured work can be anywhere from a few hours to several months. At times students who are conversational with some facilitators may need to start with structured work when communicating with a new facilitator (Biklen, 1992). Moving from structured to unstructured work usually involves semi-structured questions and answers (Biklen et al., 1992).

Attitudinal Support

It has been continuously stressed in the literature how important it is to provide emotional support to the communicator and to convey a belief in the communicator's abilities and intelligence (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992; Biklen et al., 1992; Crossley, 1991; Remington-Gurney & Crossley, 1990; Donnellan et al., 1992). By simply providing children with the means to communicate through a letter board or Canon Communicator, the message is conveyed to children that one believes they have something important to say. Speaking to children in an age appropriate manner further conveys to them that facilitators think they are capable intelligent people. Often facilitators will apologize to communicators for the simplicity of initial structured exercises (Biklen, 1990; Biklen et al., 1992).

Many children have communicated through facilitated communication how important trust is to them in their relationship with their facilitators. This appears to be critical for success (Crossley, 1988; Biklen, 1990, as cited by Crossley, 1992). Furthermore children have relayed that they cannot type with someone who does not believe they are communicating on their own volition (Biklen et al., 1992). This important component of facilitated communication has been given an almost mystical image. It has been proposed that the relationship between the communicator and the facilitator contributes just as much to the success of the technique as other aspects.

The idea that people in need work best when they feel safe and supported is not new to the human services profession (Donnellan et al., 1992). Often the client needs to have confidence in the helper and must know that the helper believes in the client's ability to succeed. McGee (1990) emphasizes the relationship between caregivers and individuals with disabilities as an essential part of his gentle teaching. He uses this approach when working with people with challenging behaviours (Donnellan et al., 1992).

The Role of Touch in Facilitated Communication

The belief that speech must precede literacy has been generally accepted, and indeed it was this that for years convinced people that deaf and mute people were intellectually impaired (Crossley, 1992). Augmentative and alternative communication methods have really only come into being in the last twenty years (McNaughton, 1990, as cited by Crossley, 1992). The use of these alternative methods has been fuelled by the progress of computer technology. This has indeed helped people with severe physical difficulties, such as cerebral palsy, to express their intelligence. Without these alternative means of communication many physically disabled people have been assumed to be profoundly intellectually impaired, as measuring their intelligence cannot be reliably assessed (Crossley, 1992).

The fact that facilitated communication requires someone to assist the communicator in the process of communication has been at the root of much of the controversy surrounding it. Touch has been viewed as "important in overcoming movement and other difficulties that result from complex neurological phenomena"

(Donnellan et al., p. 72, 1992). Furthermore, the use of touch to facilitate teaching a number of skills to individuals with autism has been done for years, but only now is it under scrutiny.

Professionals introducing facilitated communication to their clients stress that physical touch is not used to overpower the communicator. Physical touch, however, is sometimes used as a corrective measure by holding back the children's hands if they are going for an incorrect letter, or perseverating on a key. Therefore, at least in the preliminary stages, facilitated communication may bear resemblance to other types of physical assistance (physical prompting or priming). This does not imply that facilitation and prompting are the same thing, but both support the notion that touch may be a crucial sense modality for children with autism (Donnellan et al., 1992).

Not only has touch been viewed as a more effective way to teach children with autism, but it also been seen as easier to fade than verbal prompts (Donnellan, 1980; Donnellan & Mirenda, 1984; Donnellan, LaVigna, Negri-Shoultz, & Fassbender, 1988) (Donnellan et al., 1992). The assumption has been that physical prompts do not need to occur in the line of vision, therefore not interrupting the task. They also do not require verbal language for nonverbal tasks (Donnellan et al., 1992).

However, in the past, physical support has been recommended only as a last resort. In the hierarchy of prompts, physical support is used only if the person cannot perform with a verbal prompt alone. The physical prompt is then faded out so the person completes the task with the verbal prompt only. As a consequence the verbal prompt is never faded out. This leads one to question just what physical and

verbal prompts come to mean to children with autism. The fact that verbal instruction is often followed by physical assistance could mean that after a while the behaviour comes to appear more automatic only when a verbal prompt is provided. In other words, the verbal prompt becomes a discriminative stimuli which sets the scene for a certain type of behaviour (Donnellan et al., 1992).

Oppenheim (1974) wrote that hand-over-hand teaching was often necessary because children with autism often have poor motor control. Even after a child learned to write through touch, the child many times still required a hand on the shoulder. She noticed that some children with autism exhibited difficulty executing a one-finger point (Oppenheim, 1974).

The type of physical support required varies from child to child, as well as from facilitator to facilitator (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen et al., 1992; Crossley, 1991; Crossley, 1992). Some children only require a touch to boost their confidence, while others may need full support in order to control and shape movement. Facilitated communication is necessary for certain individuals due to poor eye/hand coordination, impulsiveness, perseveration, low or high muscle tone, problems isolating the index finger thus requiring two hands for tasks which normally require one, tremors, radial/ulnar muscle instability, initiation problems, impaired proximal stability, reduced proprioception, and lack of confidence (Crossley, 1991; Crossley, 1992; Crossley & Remington-Gurney, 1992)). Although some of these problems listed above do not necessarily afflict people with autism, quite a few of them do (Biklen et al., 1991). It has been evidenced that fading

physical support too quickly can lead to a breakdown in communication. The student may lose the ability to type original thoughts and regress back to echolalic sentences or perseverations (Biklen et al., 1992). Some have relayed to the facilitator that they still need the physical support to type (Biklen et al., 1991).

Maintaining Focus

The facilitator keeps the communicator focused on the keyboard or other communication aid. Often children must be controlled from displaying extraneous behaviours such as flaying arms or biting. If children verbalize echoes, they are instructed to type what they mean (Biklen & Schubert, 1991; Biklen, 1992).

Generalizing

Students will often progress quite well with one or two facilitators and will need continued encouragement to work with a number of different facilitators. This takes training by both parties (Biklen & Schubert, 1991; Biklen, 1992).

Fading

Fading is a very important component to the technique of facilitated communication in order to make independence more obtainable. As students become more independent in their ability to type it is important to fade physical support (Biklen & Schubert, 1991; Biklen, 1992; Crossley, 1991).

Echoed Language and Facilitated Communication

In the Biklen et al. (1992) study to investigate the implications of facilitated communication on the children using it, 29 of the 43 participants had primarily echolalic speech, resulting in limited conversational speech. Two of the children had great difficulty avoiding typing echoes, even when instructed to try to type their own thoughts. Many of these echoes contained the verbal instructions facilitators had given. As a result, facilitators began to type instructions, rather than say them. This appeared to work, as the children were then able to type their own thoughts. Over time facilitators were able to verbalize instructions without the students reverting back to typing echoes (Biklen et al., 1992).

Many children who are echolalic tend to type echoes if unassisted. In other words, they require facilitation in order to type original thought. Others require more structured work. If facilitation is faded before the child is ready, at times the child may regress and begin to type echoes (Biklen et al., 1992). It is important to note here that Goodwin and Goodwin (1969) reported that children with autism were able to type echoes on an electronic typewriter unassisted (Goodwin & Goodwin, 1969). One can only wonder what might have transpired if these children had been given some assistance. As mentioned earlier, many children may continue to verbalize or sign echoes while typing original thought (Vandervelde, 1992; Biklen et al., 1991). Some children, while typing original language, typed echoed or irrelevant language in the early stages. When this occurred some would backspace over these passages and then continued to type original language (Biklen et al., 1992).

Evidence of Valid Communication

Proponents of facilitated communication have cited what they believe to be proof that children using facilitated communication are communicating their own thoughts (Biklen & Schubert, 1991; Biklen et al., 1991; Biklen et al., 1992; Silliman, 1992). Biklen (1991, 1991 & 1992) has noted six factors that appear to validate the authenticity of children's typed communication.

1. **The style, speed, and accuracy of a student's fine motor control movement to the letters or keys is fairly constant across facilitators.** In this way students demonstrated their own unique behaviours while accessing communication boards or communicators (i.e.,- standing, rocking, postures).
2. **Individuals make typographical errors that are unique to them. Some individuals fairly consistently hit more than one key at a time when typing.**
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.** Instances of phonetic and creative spellings tend to occur more in younger children than older ones, which is fairly consistent with "normal" children.
4. **Some individuals type phrases or sentences that are unusual and would not be expected from the facilitators.** For example, in anger some children have sworn at

their facilitators or expressed displeasure with them. Others have used abbreviated forms of words, which often requires clarification for the facilitator.

5. Individuals sometimes produce content that is not known to the facilitator. Some children have typed out events that have occurred in their homes, about which the facilitator had no way of knowing.

6. Perhaps most impressive and satisfying, through facilitated communication individuals reveal their personalities. Sarcasm, humour, low self-esteem, and complaints have all been revealed in the typed communication of children with autism.

Biklen and Schubert (1991) also state the fact that the level of independence appears to vary from student to student and from facilitator to facilitator (Biklen & Schubert, 1991).

Not a Cure of Autism

It is extremely important to note that facilitated communication does not propose to be a cure for the autistic syndrome. The autistic behaviours continue even during sessions where a child is typing original language.

When children did become proficient at the technique many were able to comment on their inappropriate behaviours (Vandervelde, 1992; Biklen et al., 1991). For example, one seven-year-old was able to say that his tantrums were due to being upset about certain events or situations (Biklen et al., 1991). As mentioned earlier

it has been hypothesized that children with autism may display inappropriate behaviours because of some internal thought processes (GC, 1991). When speaking about their tendency to tantrum or be aggressive to themselves or others, many children with autism have attributed this to frustration and a lack of control (Biklen et al., 1992). None of the children described in the literature examined by this researcher have stopped their unusual and stereotypical behaviours (Biklen & Schubert, 1991; Biklen et al., 1991; Biklen et al., 1992).

In their 1992 study, Biklen et al., did report that some students did appear to be more in control of their behaviours, however they are reluctant to draw positive conclusions about this. This is due to the fact that for many of these children, there were still periods when their behaviours were aggressive. The researchers propose that some students were in better control of their behaviours possibly because of their involvement in academic classes (Biklen et al., 1992).

As mentioned earlier, it has been hypothesized that children with autism display inappropriate behaviour due to their frustration of not being able to communicate (Carr & Durrand, 1987). We now see, however, that even being able to communicate does not change their inappropriate behaviours significantly; at least at this point it does not seem to. The syndrome of autism itself appears to be the source of frustration, as many children have been able to say that they cannot control their behaviours. Many children have also communicated that they wish they were normal, and that it is upsetting when people think they are retarded (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992; Biklen et al., 1992).

QUANTITATIVE STUDIES

Studies on whether individuals are indeed communicating on their own volition have by and large been made up of strategies chosen by lawyers or psychologists without input from speech/language pathologists or other professionals working with alternative/augmentative communication (Crossley & Remington-Gurney, 1992). Since 1986 State government enquiries have been conducted in Melbourne in order to test the validity of facilitated communication. The results of these studies were equivocal. Although there was validity established in four out of the six participants in controlled studies, the panel stated that there were some instances when the students were influenced by the facilitators (Biklen, 1990; Crossley & Remington-Gurney, 1992). Two of the four participants who failed to prove they were communicating have since gone on to type independently (Crossley & Remington-Gurney, 1992).

Testing strategies have involved a number of different procedures, such as having the facilitator look away or having both the facilitator and the communicator wear earphones (Intellectual Disability Review Panel, 1989, as cited by Crossley & Remington-Gurney, 1992). In a recent test of communication ability where the earphone method was used, a woman with severe aphasia caused by encephalitis was asked to type the answers to 40 questions under various sets of test conditions. The woman failed to supply correct answers and as a result her family retained full guardianship of her (Crossley & Remington-Gurney, 1992; Prior & Cummins, 1992).

A psychologist with "extensive expertise in the field, who had undertaken a detailed evaluation of the woman and her assistant, concluded that the client had demonstrated no capacity for independent communication while being assisted by the assistant" (Prior & Cummins, 1992, p. 336). It is not clear exactly what the psychologist's expertise consisted of. Crossley and Remington-Gurney would argue that AAC professionals need to be part of these studies (Crossley & Remington-Gurney, 1992).

Proponents of facilitated communication argue that children do not do well in controlled studies because of the pressure, and because they are being tested. As mentioned earlier, it is believed that in order for children to communicate through a facilitator, trust needs to be established and the facilitator needs to communicate a belief in the children's competency and intelligence (Biklen, 1990; Biklen et al., 1991; Biklen et al., 1991; Biklen, 1992; Rosemary-Gurney et al., 1990). Some children may give the wrong answer on purpose (Crossley & MacDonald, 1980).

CRITIQUES OF FACILITATED COMMUNICATION

According to Donnellan et al. (1992), scepticism is understandable when one considers that for years these children have only been able to communicate minimally, but through facilitated communication are now able to produce not only grammatically correct sentences, but feelings, and sophisticated abstract thought. Considering the years of research which have gone into autism, this is quite a challenge to previously accepted thought, and leaves professionals and families quite torn (Donnellan et al., 1992).

Eric Schopler, editor of the *Journal of Autism and Developmental Disorders*, feels that Biklen, in promoting the technique of facilitated communication, has ignored critical evaluations which have been implemented by government review boards in Australia (Schopler, 1992).

Silliman (1992) proposes three different stands one could take on the issue of facilitated communication: the "Clever Hans Perspective," the "Unexpected Literacy Perspective," and the "Enigma Perspective." The second perspective accepts facilitated communication as plausible. The third perspective has not accepted nor rejected the plausibility of facilitated communication. The "Clever Hans Perspective" is the perspective held by sceptics of facilitated communication (Silliman, 1992).

Clever Hans was a horse who appeared to be able to demonstrate the capacity to think, talk, and calculate if given the proper instruction. This was done by assigning numbers to letters, and the horse used a blackboard to learn the association between the letter and corresponding number. Clever Hans would tap out numbers with his hoof in order to link letters and words together, and thus would talk through his hoof. It was discovered later that Clever Hans was responding to subtle cues given by his trainer (Hediger, 1981, as cited by Silliman, 1992).

According to sceptics the Clever Hans phenomenon is occurring in cases of facilitated communication. This group continues to accept the fact that autism is a social-cognitive-language disorder, and therefore is unable to accept the claimed effectiveness of facilitated communication. Sceptics "view conclusions being drawn by proponents of facilitated communication as unwarranted by the strength and

nature of the proofs offered; therefore, conclusions lack credibility" (Silliman, 1992, p. 63).

The Argument against the Apraxia Hypothesis

Calculator (1992a) finds reports of facilitated communication to be lacking explanations as to why it works. He sees the praxis argument to be insufficient, as it does not account for the progress the communicator makes in acquiring independence. It also does not explain why different levels of support are required for different facilitators. He proposes that there is a need for controlled studies on physical and emotional support (Calculator, 1992a).

Calculator cites Rosenbek and McNeil (1991), who advise against using the terms such as "apraxia," which "carry with them inadequately tested assumptions borrowed from neurology . . . biased search for significant characters and constant differences" (p. 293, as cited by Calculator, 1992b). Haynes (1985) reports that it is difficult to delineate developmental apraxia from functional articulation problems (Calculator, 1992b).

Calculator dismisses Biklen's hypothesis that facilitation users require assistance overcoming neuromotor difficulties in light of Biklen's (1990) presentation of Louis, who within half an hour was able to access the Canon Communicator with only the facilitator's hand stretched flat over his. Later on in the session Louis typed several complex sentences (Biklen, 1990). Calculator proposes that Biklen has not accounted for such rapid progress, as the amount of motor training and practice was minimal. Rosenbek (1983) suggested that gestural reorganization could be used as

a means of facilitating speech in people with apraxia. This would involve pairing motor gestures such as finger tapping with speech so as to promote a reorganization of motor speech control. These gestures slow down an individual's rate of speech, highlight stress and rhythmic aspects, and prompt the person to attend to each syllable of an utterance (Calculator, 1992b). Calculator raises questions as to whether the physical support described by Biklen serves the same purpose (Calculator, 1992b).

According to Blakely (1983), apraxia is often accompanied by language delays and behavioural problems, such as temper tantrums, inflexibility, distractibility, aggression, excessive motor activity, and withdrawal (Calculator, 1992b). These characteristics hold some resemblance to those which constitute autism. Blakely suggests that these behaviours may be related to a person's inability to be understood (Calculator, 1992b). This has also been proposed in the area of autism (Carr & Durand, 1987). Calculator proposes there may be a population of people with autism whose diagnosis is secondary to the fact they have adopted abhorrent behaviour due to their lack of effective communication. If facilitated communication training is going to be applied effectively, we need to get a clearer understanding of for whom it is effective, why, and how it can be presented (Calculator, 1992b).

As with Calculator, the scepticism described by Silliman (1992) is grounded in the claim that facilitated communication is successful due to the fact that global apraxia may be behind initiating and following through with movement as well as movements involved in speech. This argument appears to characterize autism as a

speech production disorder, and that an inability to communicate is secondary to neuromotor difficulties. Sceptics would argue that the mere presence of echolalia provides strong evidence that the neurophysiological functioning of the oral mechanism in speech production is intact (Silliman, 1992).

Sceptics cite Hagen's (1987) profile of apraxia as an argument against the global apraxia hypothesis presented by proponents of facilitated communication. Hagen's profile does not include children; it only applies to adults and that it is typically nonlinguistic in origin. In the case of apraxia, the sensory-motor processes which regulate the initiation, execution, monitoring, and control of speech movement are disrupted. This is more graphically seen when speech involves novel routines, rather than familiar. Understanding and memory are not impaired in this case, a distinction which is not dealt with in global apraxia (Silliman, 1992).

Adult apraxia is a phonological disorder and it involves either the encoding or retrieval of phonological information. If the problems lay at a linguistic level then one would expect all areas dependent on phonological rules to be impaired. Phonological processing breakdowns have been seen in child language disorders. These breakdowns are manifested by "production breakdowns in organization and rapid motor execution of complex phonological sequences" (Catts, 1989a, 1989b, as cited by Silliman, 1992, p. 64).

Sceptics do not believe that facilitated communication research has directly or indirectly addressed these issues of phonological processing and the production of oral or written communication. They view this omission as serious on both

conceptual and empirical grounds. There has been no serious evidence of the similar motor and speech problems seen in children and adults that would justify the inference that the sources of disruption are similar (Silliman, 1992).

Manipulation Arguments

Rejecting the global apraxia hypothesis, sceptics believe that intervening variables not yet identified may be present, and thus producing the results which have been described. It may be that if certain responses are expected, then subtle non-verbal cues (including physical cues) are inadvertently being sent in order for the communicator to give the "correct" response (Silliman, 1992; Donnellan et al., 1992; Prior & Cummins, 1992). It should be noted that in recent studies conducted in order to validate facilitated communication, it is only under those conditions where both the facilitator and communicator are being shown the same picture, or asked the same question that responses are correct (Starr, 1994).

Prior and Cummins list a number of concerns they have with the technique. The first concern involves the high degree of physical intervention given by the facilitator even when it would appear that the autistic person had sufficient motor abilities to select letters independently. A second concern lies in the fact that the technique cannot be taught to, or accessed by everyone who wishes to use it. This could include members of the child's family, including parents. A third concern is that facilitators need to hold a strong belief in the technique in order for it to work. A fourth concern is the fact that many facilitators and their students resist any kind of independent assessment. Finally, from the evidence that was collected empirically,

it would appear that some communication emanated from the facilitator (Prior & Cummins, 1992).

Prior and Cummins contend that many professionals working with handicapped clients became convinced that they were influencing their clients' answers. The physical assistance given has been viewed as highly intrusive, and sceptics argue that many children with autism are not that motor-impaired as to require such intrusive measures. This aspect calls into question any communication technique that involves physical assistance. Although proponents of facilitated communication have reported that a number of students have moved on to independent communication (Biklen, 1990; Crossley & Remington-Gurney, 1992), sceptics argue that there is no hard evidence to support this claim. As well there is no hard evidence to support the claim that students communicate independently when the facilitator is not aware of the response asked of the student. Apparently there is an independent investigation in this area now underway in Queensland, Australia by Tony Attwood (Prior & Cummins, 1992).

It is Schopler's contention that because potential facilitators are told that if they do not have faith the technique will not work, facilitators are then emotionally blackmailed into being successful. They may in fact be influencing the communicator in order to be successful (Schopler, 1992).

Sceptics continue to question why physical support continues to be required after the client has learned to communicate via facilitated communication, especially in the absence of motor difficulties. The fact that some parents of children with

autism have not been successful as facilitators is puzzling, considering these children may be quite fluent with professionals (Prior & Cummins, 1992).

Prior and Cummins report the case of a mother who was facilitating with her autistic son. When she thought about the expected response, her son was able to respond correctly, but when she let her mind go blank, all that came out was "gibberish." She continued to work with her son because he seemed to enjoy outings at the centre, as well as together time with her. She also felt pressured by staff and did not want to be difficult (Prior & Cummins, 1992).

The content of the communication reported has also been problematic for sceptics. Some of the language used is not normally found in the vocabulary of young Australians. Biklen (1990) reported a conversation he had with a number of young people at DEAL, which was very complex and abstract. It had a philosophical nature to it, and resembled the type of conversation that highly educated adults would have. Sceptics view this as totally inconsistent with what is known about the language capabilities of children with autism around the world. In fact, many of these children would appear to be more competent than their non-autistic counterparts (Starr, 1994). Furthermore, it would appear that only when children are assisted are they able to type these complex sentences and thoughts (Starr, 1994; Prior & Cummins, 1992). It is important to note that Crossley has written that she expects her students to communicate in interesting and unique ways (Biklen, 1990). Prior and Cummins argue that the "giftedness" illustrated in examples given by proponents of facilitated communication is not consistent with the known population

data on autism. Finally, there is extensive documentation of a failure for children with autism to achieve spontaneous and creative language (Prior & Cummins, 1992).

Lack of Information

Calculator (1992b) is also frustrated by the lack of descriptive information provided in articles on facilitated communication, specifically referring to Biklen's 1992a article. In this article Biklen describes 3 clients. According to Calculator, the reader is never told what types of educational, social, and emotional experiences the students have had prior to them being introduced to facilitated communication. We do not know how they got to the stage of being able to communicate effectively. As a result, Calculator feels that we can only "conjecture" as to the generalizability of findings presented (Calculator, 1992b).

Calculator further argues that no information is provided with respect to the actual content and order of instruction each participant received, or of the competencies of facilitators (Calculator, 1992b). Therefore, there is no assurance that each student communicated under the same conditions, or with facilitators who were equally effective.

Ethical Concerns

Prior and Cummins (1992) feel that facilitated communication has been uncritically adopted around the world without empirical validation. They feel the reason that this occurs lies in the fact that parents of children with handicaps are highly vulnerable to miracle breakthroughs which may lead their children to

"normalcy." For this reason, Prior and Cummins argue that the necessity of empirical evidence is even more likely to be ignored. The idea of having faith and hope appears to take precedence over obtaining real data (Prior & Cummins, 1992).

In this case, facilitated communication is attractive because of the inconsistency in progress with prior techniques, such as Bliss symbols and signing. Added to this is the "unexplainable and seemingly universal feeling, among professionals and lay persons alike, that children with autism are more competent than their performance make them appear" (McLean, 1992, p. 26). This is further emphasized by portraits of "Rain Man" type savants, and contentions that echolalic speech common to autism is really an attempt by children to be socially appropriate and relevant (Prizant, 1983; Prizant & Rydall, 1984). It leads to a wish to "unlock" the potential abilities of these children (McLean, 1992).

As mentioned earlier in Chapter 1, facilitated communication follows along the same philosophical lines as the "political correctness" being emphasized in literature pertaining to the handicapped. McLean writes that new treatment is accepted more easily if it matches practitioners' philosophical beliefs. This is also the case even if it does not match objective reality (McLean, 1992).

A further consequence of embracing this "empirically unsound method," is the possible loss of special education programs which have been designed for the autistic population. If these children are now saying they are intelligent and are not getting their needs met, what happens to these hard fought for programs? The adjustments parents have had to make in order to deal with their children's handicaps also

become disrupted. Parents have felt guilty by the claims of their children that they are not intellectually impaired (Prior & Cummins, 1992). Schopler argues that facilitated communication denies the special learning needs of children with autism, as they are portrayed as having normal intelligence, but possessing impaired motor skills (Schopler, 1992).

Sceptics have been critical of the rapid embrace of this technique without the accompaniment of empirical evidence. They question the ethics involved in exposing children and families to a method which may in fact turn out to be invalid (Prior & Cummins, 1992; Schopler, 1992). There is great concern that facilitated communication represents the surfacing of yet another miracle cure, raising and then dashing the hopes of families (Donnellan et al., 1992). A major concern is that parents reading articles on facilitated communication will believe that all their children need is to be introduced to facilitated communication and they will be fluent communicators (Calculator, 1992b).

Sceptics resent the fact that they are labelled unsympathetic and unethical simply because they are cautious and want some empirical evidence regarding facilitated communication. Prior and Cummins liken the embrace of facilitated communication without empirical evidence to drug treatment which has not been tested thoroughly (Prior & Cummins, 1992).

Questions on Diagnoses of Participants

Prior and Cummins argue that many of the children in Australia documented to have communicational abilities were not diagnosed as autistic prior to their

enrolment at DEAL. They were given the diagnosis of autism as part of an enrolment process (Prior & Cummins, 1992). Furthermore, many of the individuals involved with facilitated communication have not been diagnosed as autistic. For this reason it is difficult to assess the specific relevance of facilitated communication for the autistic population (Prior & Cummins, 1992).

In an editorial comment which followed the Prior and Cummins article, Schopler writes that facilitated communication is most likely to be successful with those autistic clients who are "precocious readers, good with computers, signs, and other forms of communication facilitation" (Schopler, 1992, p. 336). Schopler further predicts that if the media hype continues without research accountability, there is a danger of setting autism services back forty years. He is referring to a time when autism was seen as an emotional disorder and that children with autism were thought to be bright, but withdrawn due to their cold, unresponsive parents (Schopler, 1992).

What has grown out of the facilitated communication movement is a situation whereby accusations of abuse are being made by clients using facilitated communication. Sceptics are concerned that these allegations, if not empirically challenged, may lead to false convictions and incarcerations.

EDUCATIONAL ISSUES

It has been stated in the past that children with autism have special needs when it comes to education. They require structure, intrusive behavioural techniques, and a high teacher-student ratio. It is believed that because of their cognitive problems due to poor sensory integration, learning is much slower and their style of

learning is altogether different (Moroz, 1989). These special requirements make integration appear impossible, due to the special learning needs of children with autism.

According to Biklen, children diagnosed as autistic expressed a desire to be in a regular classroom, and some have even wanted to go to college (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991). Remington-Gurney and Crossley suggest that education professionals need to be trained in facilitated communication and willing to try it in order for it to be successful (Remington-Gurney & Crossley, 1990).

When parents were surveyed in Melbourne it was found that they now viewed integration more positively because of their children's new found communication skills through facilitated communication, the opportunity to interact with "normal peers," and the anticipation of a better quality of life (Remington-Gurney & Crossley, 1990).

Educators were also surveyed as to what they viewed as the long-term benefits for the students using facilitated communication. The benefits are listed in rank order as follows: i) independent use of the communication device; ii) greater socialization with peers; iii) general improvement in the quality of life; iv) academic accomplishment; v) post-tertiary education; and vi) employment in the community (Remington-Gurney & Crossley, 1990).

Remington-Gurney and Crossley contend that children using facilitated communication in integrated classrooms are more dependent than other disabled

children. They are often slower to initiate conversations and form relationships. As a result, self-esteem, emotional and psychological development are very vulnerable. Although there is much evidence indicating that integrated students tend to perform better academically when compared to their segregated counterparts, very little research has been done on the psychological and emotional outcomes of integration and differences in teacher expectations and instruction delivery which precede improved academic outcome (Remington-Gurney & Crossley, 1990).

COMMUNICATION AND PARENTAL STRESS

For parents, the inability of their children to communicate is a major source of stress (Prizant & Wetherby, 1988; DeMyer, 1979, Wing, 1980; Lapin & Lapin, 1976; Donovan, 1988; Marcus, 1977). Many parents, after years of trying to communicate with their children, give up. Because their children do not respond to them, parents are often left feeling useless and unwanted. When children are in distress parents are left feeling like failures because of their inability to comfort their children (Wing, 1980; Marcus, 1977). Facilitated communication may finally be a way parents can talk to their children and for both parties to communicate feelings and needs to each other.

However, as mentioned in an earlier section, it is exactly for the reasons above that sceptics are worried about how quickly facilitated communication has been embraced without valid empirical evidence. They feel that parents are very vulnerable to facilitated communication because it holds a key to "unlock" their

children from not being able to communicate (Prior & Cummins, 1992; Schopler, 1992; Silliman, 1992).

CONCEPTUAL FRAMEWORK

Television shows such as 20/20 and W5 have investigated facilitated communication and interviewed parents and professionals regarding their thoughts on the technique. As far as this researcher has been able to determine there has not been a study on the responses or experiences of this group in regard to facilitated communication. This is an important area of study, as the responses of this group are important to the children who are using facilitated communication. Support is essential for it to be successful. Autism not only impairs an individual's response to the environment, but also results in the whole family unit struggling to come to terms with its effects (Kostanareas, 1990; Harris, 1984; Bristol, 1985; Salomon, 1981).

Stressors which often accompany a family's struggle to care and support the child with autism suggest how important family intervention is. A family system approach, sometimes called a "psychoeducational approach," has grown out of the belief that autism is biologically based (Kostanareas, 1990; Harris, 1984; Kalmanson & Perkarsky, 1987; Bristol, 1985). It is imperative that intervention begin as soon as possible following diagnosis. This vastly improves prognosis for the child and increases the likelihood that the child and family will be able to cope (Prizant et al., 1988; Kostanareas, 1990). Families need to be empowered to make informed decisions on behalf of their child and the focus of intervention needs to be relieving

stress, increasing communication between marital partners, teaching parents behaviour modification, and working with educational programs.

A family systems approach looks at the whole functioning of the family and makes systematic assessments. A major focus of this approach is to examine family stressors, attempting to decipher which factors alleviate stress and which ones contribute. During this assessment the clinician is interested in relationships between family members, personality characteristics, and community resources available to the family (Kostantareas, 1990; Harris, 1984; Bristol, 1985; Salomon, 1981). The goal of the psychoeducational approach is for parents to become partners with the clinician in working with autistic children (Harris, 1984; Bristol, 1985; Moroz, 1989; Prizant et al., 1988).

An important part of making parents co-partners in their children's treatment is to get them involved with their children's education. The availability of resources can be improved upon through conjoint work with the school and the therapist. Parents come into contact with other parents who have autistic children (Moroz, 1989). When parents work through a centre it helps to combat against their feelings of isolation. Out of school and community resources parents may find informal and formal support groups. Parents working together can be strong advocates for much needed services (Prizant et al., 1988; Wintersteen, 1988).

The theory behind the family systems approach is that intervention in one area of family functioning will ultimately effect other areas. Mentioned earlier in this report is the fact that for many parents their children's lack of communication is a

major source of stress. If facilitated communication can be used to improve a child's ability to communicate, then parents may feel much less stressed in this area. This is especially true if parents can be part of this process. Parents may also worry less about their children's futures and feel better about the level of independence their children can achieve. Not only will their feelings of competency improve, but they will also have a more positive outlook in their ability to intervene with their children. Parents may have more time and energy to work on other areas of stress (Harris, 1984).

It has been suggested in an earlier section that facilitated communication will increase the likelihood of integration for children with autism. In the study conducted in Melbourne, Australia regarding facilitated communication and integration parents were asked to report changes within the family network since integration. Changes include the following:

- i) students forming new friends
- ii) increased participation in social and recreational activities
- iii) increased parental involvement in meetings e.g.- integration support meetings
(this was often recorded as an added stress)
- iv) increase in more appropriate behaviour
- v) students appear happier, more relaxed and fulfilled
- vi) student is more socially responsive
- vii) improved verbal communication skills
- viii) improved self-esteem

- ix) opportunity for greater generalization and development of communication and life skills
- x) chance to become an integral community member at all levels (Remington-Gurney & Crossley, 1990)

It is important to note that it is not clear how some of these variables such as self-esteem have been measured. However, it would appear that generally these children are fairing better in their home environment as a result of a chance of normalization.

RESEARCH QUESTION

The purpose of this study is to explore the experiences of parents, their children diagnosed as autistic, and professionals with the technique of facilitated communication.

Operationalization of Variables

Experiences will be operationalized through family demographics, children's behaviours, children's IQ/functioning level, age at diagnosis, school, children's communication characteristics, involvement/interest in facilitated communication, and emotional response to children's success at facilitated communication. Included in the appendices are the questionnaires to be given to parents and professionals, and this should relay further operationalizations of **experiences**.

Facilitated communication is operationalized as a technique whereby an individual communicates with the physical and emotional support of another

individual known as a facilitator, by pointing to objects, pictures or letters. The degree of physical support given varies depending on the needs of the individual, but it most commonly involves slowing the person's movements down by providing counter-resistance and pulling his hand back after each response.

Autism is operationalized through the diagnosis given by a physician. The children in this study have already been diagnosed as autistic by DSM-III-R criteria.

Children include the natural or adopted offspring of parents involved in the parent support group operating through the Society for the Treatment of Autism, who may or may not be using facilitated communication. When addressing professionals these children are referred to as **clients**, and they consist of children who are involved with the Society for the Treatment of Autism who may or may not be using facilitated communication.

Parents include natural, step, and adopted parents who have some knowledge of facilitated communication and who are involved with the parent support group operating through the Society for the Treatment of Autism.

Professionals include social workers, teachers, child care workers, speech pathologists, psychologists, and psychiatrists. A youth worker will be considered the same as a child care worker. All professionals in this study have some knowledge of facilitated communication and are connected with the Society for the Treatment of Autism.

SUMMARY

This chapter reviewed the literature on autism, including characteristics of autism and hypotheses surrounding this syndrome. Literature on facilitated communication was also discussed, including qualitative and quantitative studies, the mechanics of facilitated communication, and critiques of this technique. Communication and parental stress, educational issues and a conceptual framework was included in the discussion. Lastly, this chapter concluded with an outline of the research question and variables employed in this study.

CHAPTER 3

METHODOLOGY

INTRODUCTION

This chapter describes the research design utilized for the study, as well as the study setting. Also discussed will be a description of the populations, the development of the measurement tools, data collection procedures, and threats to internal and external validity.

RESEARCH DESIGN

An ex-post facto design, XO, will be utilized in this research. This study is intended to explore the experiences of professionals and families in regard to facilitated communication. Ex-post facto designs are primarily used as "stepping stones" to more controlled and extensive studies on those issues which are often highlighted in exploratory studies (Epstein, 1988; Grinnell & Stothers, 1988).

THE SETTING

The setting for this study is the Society for the Treatment of Autism. This agency provides a number of services for children with autism and their families in a city of 800,000 and the surrounding regions. The agency has a residential care facility which provides milieu therapy and infant development programs through the use of a comprehensive professional team. The Society further offers: assessment services; family counselling and management; an out-patient program; a post-

discharge follow-up; weekend care; teaching seminars; child management sessions; and community integration into schools and clubs. A parent support group is offered for parents of children diagnosed as autistic who may or may not be involved with the Society. The Society offers information to the general public, and has sponsored conferences and workshops for parents and professionals involved with individuals with autism.

THE POPULATIONS

The populations included those parents, professionals, and children involved with the Society for the Treatment of Autism. The sample included those parents and professionals who had knowledge of facilitated communication in September and October, 1992 when the study was initiated. All participants volunteered to be part of the study.

Availability sampling was used. Eleven parents comprised the parent sample, and eleven children comprised the child sample. Although some children in the sample were clearly adults chronologically, in this study they will be referred to as children since they are the children of the parents reporting. The professional sample was made up of sixteen professionals.

The Parents

Parents in this study were those parents who attended the parent support meeting on September 15, 1992. Also included were those parents who completed a questionnaire given to them by members of the parent support group and who

mailed it back to the Society. Of the eleven parents who volunteered, eight were mothers and three were fathers.

Five of the parents fell in the 40 to 49 year age group. Four fell in the 30 to 39 year age group. One parent was 59 years of age and one was in the 20 to 29 year age group (see Table 3.1).

Table 3.1

Age of Parents (N= 11)

Age	Number(%)
20-29 years	1 (9.1)
30-39 years	4 (36.4)
40-49 years	5 (45.5)
50-59 years	1 (9.1)
Total	11 (100.0)

Some parents reported disabilities afflicting other family members. These reported disabilities included mentally challenged, learning disabled, and pervasive developmental disorder not otherwise specified. One parent reported a number of disabilities afflicting family members. These difficulties included dyslexia, cerebral palsy, seizures, and mental handicaps. However, most parents reported they did not know of any disabilities.

Six of the parents noticed problems with their child when the child was between 13 and 24 months of age. Four noticed problems when the child was

between two to three years of age. One parent noticed a problem within the first three months of the child's life.

The Children

Information about the children was obtained from the parent sample. The children ranged in age from 4 to 28 years, with the mean age being 11 years (see Table 3.2). Nine of the children were male and two were female.

Table 3.2

Ages of Children (N=11)

Age	Number(%)
4	1 (9.1)
6	3 (27.3)
9	2 (18.2)
10	1 (9.1)
16	2 (18.2)
20	1 (9.1)
28	1 (9.1)
Total	11 (100.0)

The initial diagnosis of autism occurred at different ages for the children. Four of the children were diagnosed as autistic between two and three years of age, four between three and four years of age, and two were diagnosed after the age of

four. Only ten parents answered this question (see Table 3.3). One parent wrote that her child has never been formally diagnosed as autistic.

Table 3.3

Age of Child When First Diagnosed (N=10)

Age	Number(%)
Between Two and Three Years	4 (40.0)
Between Three and Fours Years	4 (40.0)
After Four Years	2 (20.0)
Total	10 (91.0)

Nine of these children had been assessed as functioning well under their chronological age, one child slightly under chronological age level, and one child at age level. Of the children, eight were living at home, one in a group home, and two in a treatment centre.

The Professionals

The professionals in the sample comprised of eleven child care workers, two child care worker supervisors, one assessment worker, one psychological assistant, and one social worker (see Table 3.4).

Table 3.4**Primary Responsibility of Agency Professional (N=16)**

Responsibility	Number (%)
Child Care Worker	11 (68.8)
Supervisor	2 (12.5)
Assessment Worker	1 (6.3)
Psychological Assistant	1 (6.3)
Social Worker	1 (6.3)
Total	16 (100.0)

Experience among the professionals varied similarly. Thirteen professional workers had one to five years experience at their profession and three professionals had six to ten years experience. Thirteen professionals had been employed specifically with the Society for one to five years, while two had been employed with the Society for less than a year. One professional had been with the Society for six to ten years (see Table 3.5). Thirteen of the professionals were between 20 and 29 years of age, while three were between 30 and 39 years of age; thus all were quite young. Fourteen professionals were female and two were males.

Table 3.5**Years Employed with Present Employer (N=16)**

Years	Number(%)
Less than 1 year	2 (12.5)
1-5 years	13 (81.3)
6-10 years	1 (6.3)
Total	16 (100.0)

THE DEVELOPMENT OF THE MEASUREMENT TOOLS

Two questionnaires were developed by this researcher in order to implement this study: (1) the parent questionnaire (Appendix B); and (2) the professional questionnaire (Appendix D).

The Parent Questionnaire

The parent questionnaire consisted of six sections: (1) family demographics; (2) child's behaviours; (3) child's communication history; (4) child's school experience; (5) parents' and child's experience with facilitated communication; and (6) parental concerns.

No standardized measurement tools were identified that would adequately address these areas. Questions were developed from the literature and Rimland's Diagnostic Checklist for Behaviour-Disturbed Children (Form E-2) (Rimland, 1980).

Utilizing the E-2 in its entirety was not suitable, as it was developed for children under six years of age, and therefore would not be appropriate for the age range this study involved. Five questions were transferred directly from the E-2 to the behaviour and communication sections of the questionnaire. The E-2 has been established as reliable and valid.

This Checklist can be completed by parents, and does not necessitate a trained psychologist or psychiatrist to fill it out. The parent questionnaire was also developed out of this researcher's own research on autism and its characteristics, and through consultation with experts.

The Professional Questionnaire

The professional questionnaire consisted of three sections: (1) professional characteristics; (2) professional experience with facilitated communication; and (3) professional and clients' education experience. All sections were developed through this researcher's consultation with experts and a review of the literature.

ESTABLISHING FACE VALIDITY

In order to establish face validity this researcher had both parent and professional questionnaires reviewed by the social worker and speech pathologist at the Society for the Treatment of Autism between July 29, 1992 and August 5, 1992. These professionals can be considered as experts in the area of autism and facilitated communication.

The Parent Questionnaire

This process of validation resulted in some questions being eliminated from the parent questionnaire. Questions eliminated included those pertaining to ethnicity, and stress levels of parents before and after the introduction of facilitated communication. It was agreed by all parties that ethnicity was irrelevant due to the fact that autism can be found in all ethnic groups. Questioning parents on their stress levels may have the potential to be viewed as implying they are responsible for the autism, therefore, these two questions were eliminated. Other changes made were editorial in nature, consisting of adding to item selections, expanding definitions of variables, and re-wording some questions.

The Professional Questionnaire

Review of the professional questionnaire consisted of the same process, with all parties agreeing with the changes that resulted. Revisions to the professional questionnaire consisted of adding to item selections, and expanding and refining definitions of variables. Some questions were re-worded but the general meaning of them was not altered.

DATA COLLECTION PROCEDURES

This section discusses the administration of the measurements and the process of data collection. A summary is provided through Table 3.6.

Table 3.6
Summary of Data Collection Process

July 29, 1992	Contact with President of Parent Support Group.
September 9, 1992	Follow-up with President.
September 10, 1992	Contact with Executive Director of Agency.
September 15, 1992	Administration of Parent Questionnaire.
September 17, 1992	Professional Questionnaires distributed.
September 28, 1992	Completed Professional Questionnaires retrieved.
	Reminder letters distributed.
October 7, 1992	Mailed in Parent Questionnaires retrieved.
	Completed Professional Questionnaires retrieved.
October 14, 1992	Mailed in Parent Questionnaires Retrieved.

The Administration of the Parent Questionnaire

On July 29, 1992 this researcher contacted the president of the Parent Support Group in order to discuss attending a parent support meeting with the intention of administering the questionnaire. The next meeting was scheduled for September 15th at 7:00pm at the residential program. It was agreed that the questionnaires could be given out at 6:30pm prior to the start of the meeting's regular business.

This phone call was followed up by another call on September 9, to confirm plans for implementation of the study. The scheduled time was changed to 7:00pm since many parents had a hard time getting to meetings any sooner.

On September 15, this researcher attended the parent support meeting. The meeting began right at 7:00pm; eleven parents and the social worker with which this researcher had previously consulted were present. Introductions were made and the study was presented by reading the cover letter/informed consent form (Appendix A). Parents were also informed of their need to sign the consent form and to indicate if they would like a summary of the results of the study. The questionnaires were handed out and parents were also told that their child need not have tried facilitated communication; parents only had to know what it was. Parents were invited to ask questions at any time during the study.

One man asked for further clarification of what was going to be done with the results. The need for a comprehensive picture of a group of parents and their experiences with facilitated communication and autism was explained. It is important to understand parents' experiences and perceptions about facilitated communication, as their answers may be influenced by their child's communication history, and the degree of autism their child has. Clarification was needed for question 1.10 because one man's son had an uneven skill level, and it was hard to comment on the child's exact functioning level. He was told to answer the best he could. The same man commented later on the fact that for Section II the scales were labelled such that "Never" was on the left end and "Always" was on the right end of the scale. For question 5.11 the scale is somewhat reversed that "High level" is on the left end and "Low level" is on the right end of the scale. The man wondered if this may confuse some people.

All participants completed the questionnaire within the half hour allotted time frame. Questionnaires and signed consent forms were handed back. Nine parents completed the questionnaire. One parent abstained, and one couple completed one together. In closing, parents were told that it would be very helpful to get more personalized accounts of their experiences via short interviews. Parents were invited to leave their names with the group president if they would be willing to participate in an interview. Some parents indicated that they would be interested. Since not all members of the group had attended the meeting, extra questionnaires were provided to the president for mailing. These questionnaires would be returned to the Society and later collected by this researcher. Participants were thanked for their input and cooperation.

On October 2, the president of the Parent Support Group informed this researcher that a parent who was not at the meeting had returned a completed questionnaire. The questionnaire was picked up on October 7. On October 14 the social worker with the Society informed this researcher that another parent had dropped off a completed questionnaire at the Society. At this time, it was decided that this would be the last questionnaire accepted, and the questionnaire was collected at reception. This brought the total parent sample to eleven.

The Administration of the Professional Questionnaire

On September 10, the Executive Director of the Society for the Treatment of Autism was contacted for permission to administer questionnaires to the staff; permission was granted.

On September 17, 25 professional questionnaires were distributed among staff members at the agency. A box was left at reception. Each envelope contained a cover letter/informed consent form (Appendix C) and a questionnaire (Appendix D). Participants were asked to complete the questionnaire, sign the consent form, seal both in the envelope provided and then place it in a box at reception, to be picked up by this researcher.

On September 28, fourteen questionnaires had been returned. Reminder letters (Appendix E) were sent to staff members' mailboxes regarding unanswered questionnaires.

On October 7, two more completed questionnaires were collected, bringing the sample total to sixteen. At this time, the box was removed from reception.

UNSTRUCTURED INTERVIEWS

The Parents

On October 2, this researcher spoke to the president of the parent support group in order to ask her about informal contacts with parents. She indicated that a small group of parents would be meeting on October 7 at 7:00pm for a facilitator training session with the speech pathologist. These parents were facilitating with their own children. This researcher was invited to stop by at 9:00pm when the session was over.

At 9:30pm this researcher went into the meeting. Much time was spent in a group discussing facilitated communication and future ramifications (school,

employment). Information yielded during this session is consistent with responses to the open-ended questions in the questionnaire. Although parents has a lot of hope as to what facilitated communication could mean for their children they did not expect miracles.

They knew that not all children will be fluent with facilitated communication. All believed that their children hold many abilities that they are unable to express due to their autism. They hoped their children could become more employable with the help of facilitated communication. They were, however, realistic about how "user friendly" facilitated communication could be in the community. It is important to note that one woman tried to purposely guide her son's hand and he became angry and ended the session.

The Professionals

This researcher spoke to a child care worker about her own personal experience with facilitated communication while employed at the residential program on October 7. Again, her responses were consistent with those in the open-ended question on the questionnaire.

She stated that in order for one to truly believe in facilitated communication, one had to act as a facilitator. She felt that it opened up many options for people, but acknowledged that much of it depended on situations and the community being able to support facilitated communication. If the child was not given the proper tools, time, and physical support, nothing would change about that child's life. She was a strong advocate for the use of facilitated communication in the classroom, and

said that in her experience most schools were open to it. Above all, she felt that every child has a right to try facilitated communication.

THREATS TO INTERNAL AND EXTERNAL VALIDITY

Several issues are possible threats to the internal and external validity of this study.

Internal Validity Threats

The research design utilized in this study has no internal validity. It is very difficult to control for extraneous variables such as maturation, differential selection of subjects, and interaction effects.

The measurement tools had no validity or reliability; this is also a threat and is called "instrumentation." Much of the parent questionnaire relies on memory and this can be a source of error as parents may have trouble recalling information accurately. They may have forgotten how "good" or "bad" things were, which may lead to a sort of "whitewash" of history.

External Validity Threats

Generalization of the findings of this study to the population in other geographical regions is not possible. This is called selection-treatment interaction. The fact that the sample sizes are relatively small can also be problematic.

Finally, the samples may be biased due to the fact that the agency is a strong advocate for facilitated communication and there may be pressure to comply with this bias for both parents and professionals.

SUMMARY

The research design used in this exploratory study is an **ex-post facto design**.

The setting used in accessing the population was the Society for the Treatment of Autism. The populations studied included parents, their children, and professionals involved with the Society for the Treatment of Autism.

Data on parents and children was collected via the parent questionnaire (Appendix B) at a parent support meeting, and also by members giving questionnaires to those who could not attend the meeting. Further data was obtained through an informal discussion with the speech pathologist and several parents who are learning to facilitate with their children.

Data on the professionals were obtained through professional questionnaires (Appendix D) which were distributed in their mailboxes at the Society. An unstructured interview was held with a child care worker.

There are a number of threats to the internal and external validity of this study which need to be considered, such as extraneous variables and samples which may be biased in favour of facilitated communication.

CHAPTER 4

DATA ANALYSIS AND FINDINGS

INTRODUCTION

This chapter describes the results of the study in regard to parent and child variables, and professional variables. A discussion on the comparison of parents and professionals on certain issues will follow. Other study findings, such as interviews and open-ended questions on the questionnaires will also be discussed.

THE RESEARCH QUESTION

This study attempts to answer the question: What are the experiences of parents, children with autism, and professionals with facilitated communication?

THE PARENTS AND CHILDREN

This information was gathered through the parent questionnaire (Appendix B). Findings will be presented in the same order as the questions on the questionnaire. Demographic data has already been presented in Chapter 3.

Behavioural Characteristics

Table 4.1 lists a number of behaviours common to the autistic syndrome, and the number of parents in the sample who found these behaviours to be a problem. Areas reported to be most problematic were chanting and singing, and ritualistic behaviours; these were reported as problematic by nine of the parents.

Table 4.1**Parents' Perceptions of Children's Behaviours**

Behaviours	Number Perceiving Behaviour as Problem (%)	N (%)
tantrums	4 (36.4)	11 (100)
aggression	4 (36.4)	11 (100)
self-abusive	3 (27.3)	11 (100)
stereotypical behaviours	8 (72.7)	11 (100)
destroys objects/clothing	4 (36.4)	11 (100)
chants and sings	9 (81.8)	11 (100)
fixations	8 (72.7)	11 (100)
oblivious of environment	7 (63.6)	11 (100)
overly sensitive	8 (72.7)	11 (100)
odd and impaired mobility	2 (18.2)	11 (100)
repetitive play	8 (80.0)	10 (91)
need for sameness	6 (54.5)	11 (100)
lines objects up	4 (40.0)	10 (91)
avoids eye contact	7 (63.6)	11 (100)
avoids contact with others	7 (63.6)	11 (100)
toileting problems	4 (36.4)	11 (100)
masturbates	5 (45.5)	11 (100)
ritualistic behaviours	9 (81.8)	11 (100)
hyperactive	6 (54.5)	11 (100)
lethargic	3 (27.3)	11 (100)
mouths/eats inedibles	3 (27.3)	11 (100)
laughs inappropriately	6 (54.5)	11 (100)

Eight parents reported stereotypical behaviours, fixations, over sensitivity, and repetitive play as problematic. The least problematic was odd and impaired mobility, only being reported as such by two parents.

Originally, Table 4.1 data was collected through questions set up as category partition scales, ranging from 1 to 5, with 1 indicating "Never" and 5 indicating "Always". The data was then recoded so that numbers 1 & 2 would indicate there was no problem, and 3, 4, & 5 would indicate that there was a problem. This recoding was done in order to create a dichotomous variable, thus establishing the behaviour was either a problem or it was not a problem. With the category partition scales, parents were given a wider choice when rating the severity of the problem.

None of the parents reported their children to have extremely unusual skills. In other words there were no "savants" among the children. Two parents indicated that their children were good at jigsaw puzzles. Other skills mentioned by parents were a sense of rhythm, musical pitch, and throwing and catching a ball. One parent reported his child to be good at spelling with facilitated communication.

Eight parents reported their children demonstrated extreme fears, either of people, animals, or both. Five were fearful of certain animals, and three of people and animals.

Five parents reported that their children exhibited somewhat below average physical coordination. Five parents reported their children demonstrated odd postures sometimes or often. Nine parents reported their children to be a little or very awkward when attempting fine motor skill work.

Communication History

Prior to their children being introduced to facilitated communication, four parents felt that they had a low level of understanding of the spoken word. Five felt they had a medium level, and only two thought their children had a high level. This suggests that the majority of parents felt their children did have problems understanding language.

Table 4.2 shows the age that children in the sample began to talk (if ever), based on their parents' recollection. Four began talking between 8 and 12 months of age. One child has never spoken. However, eight showed little or no progress in their speech ability. Four children stopped speaking and have never spoken again.

Table 4.2

Parents' Recollection of Child's Age at Time of First Words (N = 11)

Age	Number (%)	
Never used words	1	(9.1)
8-12 months	4	(36.4)
13-15 months	2	(18.2)
16-25 months	2	(18.2)
2-3 years	2	(18.2)
Total	11	(100.0)

Table 4.3 depicts the type of verbal communication children typically exhibited. Three children were reported as having no verbal communication. Five

demonstrated a combination of echoed and original language. None demonstrated all original language.

Table 4.3

Parents' Perception of Typical Verbal Communication of Child (N= 11)

Verbal Communication	Number (%)
No verbal communication	3 (27.3)
Single words or word approximations	1 (9.1)
Two-word phrases	1 (9.1)
Echoed words/sentences, delayed or immediate	1 (9.1)
Combo of echoed and original words/sentences	5 (45.5)
Total	11 (100.0)

Table 4.4 lists types of communication techniques and the number of children in the sample who had been exposed to each type. Many children had been exposed to a wide variety of augmentative communication techniques, as well as speech therapy. Eight had been exposed to the latter, and seven to sign language. Two had not been exposed to any communication techniques prior to facilitated communication.

With these techniques only one child was able to use sentences. Three were able to use words, and one was able to communicate wants and needs through symbols and gestures. Three were not able to communicate. One parent did not respond.

Table 4.4**Communication Techniques and Speech Therapy Used by Children
(N = 11)**

Type of Communication	Number	(%)
Speech therapy	8	(72.7)
Sign language	7	(63.6)
Picture boards	4	(36.4)
Total communication	4	(36.4)
Gestural	3	(27.3)
Total	11	(100.0)

Education Experience

Of the sample, six children were in special education classes. Three were in integrated classes, and two were not in school. One child was only 4 years old, and another was 28 years old. It is interesting that when parents were asked if they would like their child in an integrated classroom, six stated yes. One did not want the child in an integrated classroom. Two were not sure. Two did not answer, possibly the parents of the children not in school.

When asked whether they agree or disagree with the idea that facilitated communication makes integration more possible, seven agreed, while four were neutral in their opinion. On the questionnaire, parents were given a scale of 1 through 5 to indicate their level of agreement or disagreement, with 1 being "Very much disagree," and 5 being "Very much agree." Results were recoded so that 1 and

2 indicated "disagree," 3 indicated "neutral," and 4 and 5 indicated "agree." Recoding was done in order to make the data more meaningful. The original format of the question was useful for parents, as it allowed them to have a wider choice.

Seven parents had suggested (or someone else working with their child) using facilitated communication in the classroom. Only nine parents responded to this question. Six reported the school response was positive, while one reported a neutral response. One had not approached the school. Three did not respond. Responses were recoded so that "quite positive" and "somewhat positive" would indicate "positive," and "quite negative" and "somewhat negative" would indicate "negative."

Out of nine parents who responded, only one reported that his/her child was using facilitated communication in the classroom. Five reported their children were not using facilitated communication in the classroom, but that they would like for this to happen. One mother reported that her son was going to get the opportunity this year.

Facilitated Communication

When parents were asked how they first heard about facilitated communication, five said they had heard about it through the media. Two heard about it through the treatment centre, one through autism newsletters, one through journals and articles, one from the parent of an autistic child, and one through the Autism Society.

Five parents reported their children had been exposed to facilitated communication. Two were not sure, and four reported that their children were not

involved with the technique. All five of the children using facilitated communication had been successful to varying degrees. Two were able to use sentences and single words, and three had pointed correctly to pictures and symbols. Two parents were not sure of the success of their children.

Seven parents reported that they wanted their children involved with facilitated communication. One did not, and three were not sure. Four parents had tried facilitating with their children, and had been successful to varying degrees. For two, children were able to use single words and for another two, children were able to point correctly to pictures and symbols. Two parents did not respond to the question. Seventy percent of parents wanted to facilitate with their children, while three were not sure. One parent did not respond to the question.

Only three parents had actually observed their children communicate through facilitated communication. One parent did not respond.

When asked to rate their level of confidence in the authenticity of facilitated communication, seven parents were somewhat or very confident. One parent was somewhat sceptical, and three were neutral. In order for parents to be confident, or more so, two needed to facilitate with their children, and three reported that their children needed to be successful with the technique. One parent needed to see the child be successful. One parent required more research. Four parents were confident in the authenticity of facilitated communication, and did not require further information.

When parents were asked to rate the amount of support they perceived to exist for them in regard to facilitated communication, six reported a high rate of support, three parents rated the amount of support as neutral, and one reported low support. One parent did not respond. Data was recoded so that 1 and 2 indicated "high support," 3 indicated "neutral," and 4 and 5 indicated "low support." This was done to make the data more meaningful.

Table 4.5 illustrates sources of support and the number of parents who received support from each source. Eight parents reported that the parent support group was part of their support system. For two parents, this was their sole support. Two parents did not list any supports.

Table 4.5

Sources of Support for Parents

Support	Number (%)	
Parent support group	8	(72.7)
Spouse	5	(45.5)
Professionals	5	(45.5)
School	5	(45.5)
Extended family	3	(27.3)
Friends	3	(27.3)
Children	3	(27.3)

Parents were asked if they agreed or disagreed with the statement that facilitated communication challenged theories suggesting autism is a social-cognitive-language disorder. Again parents were presented with a scale, ranging from 1 to 5,

with 1 being "Very much disagree" and 5 being "Very much agree." Data was recoded so that 1 and 2 indicated "disagree," 3 indicated "neutral," and 4 and 5 indicated "agree." Seven agreed with the statement, while two disagreed, and two were neutral.

Parents were asked if they agreed or disagreed with the statement that facilitated communication challenged the view that autism limits children's abilities to relate to and understand the world around them. Data was collected and coded the same as above. Six parents agreed with this statement, while four were neutral, and one disagreed.

Parents were asked if they agreed or disagreed with the statement that they found themselves questioning the past assessments of their children. Data was collected and coded the same as above. Four parents disagreed with this statement, while four were neutral. Three agreed with the statement. One parent who disagreed with the statement wrote on the questionnaire that he never believed the assessment in the first place.

Two parents found themselves relating to their children at a higher level since the introduction of facilitated communication. Four parents were relating the same, and three were not sure. Two parents did not respond. When asked how often they worried about their children's future prior to facilitated communication, six parents worried always or often, two worried sometimes, and one worried rarely. Two parents did not respond. When asked how often they worried about their children's

futures after the introduction of facilitated communication, six parents worried about the same, one worried less, and two were not sure. Two parents did not respond.

Table 4.6 shows areas of concern, and the number of parents in the sample who saw these areas as a concern. This section was completed by ten parents. Originally scales were given for parents to rate the level of concern they experienced in each area. Again, in order to make data more meaningful, the numbers were recoded so that 1, 2, and 3 indicated "concern," while 4 and 5 indicated "no concern." This acted as a dichotomous variable. Behaviours, communication, social skills, and safety were seen as concerns by eight parents. More than half were concerned about finances. One parent added the child's future to the list, and another listed the child's day program.

Table 4.6

Parents' Perceptions of Areas of Concern

Concern	Number Concerned(%)	N(%)
Safety	10 (100)	10 (91)
Behaviours	8 (80)	10 (91)
Communication	8 (80)	10 (91)
Social skills	8 (80)	10 (91)
Finances	6 (60)	10 (91)
Residence	5 (50)	10 (91)
Health issues	4 (40)	10 (91)
Other (future)	1 (10)	2 (20)
Other (day program)	1 (10)	2 (20)

THE PROFESSIONALS

Data was gathered via the professional questionnaire (Appendix D). Demographic data was reported in Chapter 3, and thus will not be reported in this section.

Facilitated Communication and the Classroom

When asked how they first heard about facilitated communication, nine professionals responded that they had heard about it through the workplace. Three heard about it through the media. Other sources mentioned by four of the professionals were: parents of clients, colleagues, autism newsletters, and a parent of a former client.

Professionals were asked about their position regarding the authenticity of facilitated communication. Nine were either somewhat or very confident in the technique. Three professionals were either very or somewhat sceptical in the technique. Four were neutral in their position.

When asked what needed to happen in order for them to be more confident in the technique, nine of the professionals responded that more research needed to be done. Three needed to facilitate with a child, and four felt confident in the authenticity of facilitated communication.

When asked to rate the level of support professionals felt existed in their work environment for facilitated communication, eight professionals rated it as high, six rated it as neutral, and two as low. Originally data was reported through a question with category partition scales, ranging from 1 to 5, with 1 indicating "high support,"

and 5 indicating "low support." This data was recoded so that 1 and 2 would indicate "high support," 3 would indicate "neutral," and 4 and 5 would indicate "low support." This was done in order to make the numbers more meaningful.

Twelve professionals reported to have been successful to varying degrees with the technique of facilitated communication. Five professionals reported the child was able to use sentences. One reported the child used 2-3 word phrases. Two reported the child used single words, and four reported the child was able to point to pictures/symbols. Four professionals had not yet been successful as facilitators. Of the four who had not yet been successful at facilitation, two wished to learn, and two were not sure if they wanted to learn. Fifteen had been able to observe, other than on television, a child communicate through facilitation.

Professionals were asked whether they agreed or disagreed with the statement that facilitated communication challenged theories that view autism as a social-cognitive-language disorder. Data was originally collected through Calgary Partition scales, ranging from 1 to 5, with 1 indicating "very much disagree," and 5 indicating "very much agree." Data was recoded so that 1 and 2 indicated "disagree," 3 indicated "neutral," and 4 and 5 indicated "agree." Eleven professionals agreed with the statement, while three were neutral, and two disagreed.

Professionals were then asked whether they agreed or disagreed with the statement that facilitated communication challenged the view that children with autism are severely handicapped in their ability to understand the world around

them. Data was recoded from Calgary Partition scales in the same fashion as above. Fifteen professionals agreed with this statement, while one remained neutral.

When asked whether they agreed or disagreed with the statement that they now found themselves questioning the past assessments clients had been given, ten professionals agreed, while three were neutral, and three disagreed. Again, data was recoded in the same way as above.

Ten professionals found themselves relating to their clients on a higher level than previously since the introduction to facilitated communication. Four related to clients at about the same level, and two indicated that they were not sure.

Ten professionals felt their clients had a chance to achieve a higher level of independence than previously. Three did not think so, and three were not sure.

Professionals were asked whether they agreed or disagreed with the statement that facilitated communication made the integration of children with autism more possible. Data was originally collected via category partition scales, ranging from 1 to 5, with 1 indicating "very much disagree," and 5 indicating "very much agree." Data was recoded so that 1 and 2 indicated "disagree," 3 indicated "neutral," and 4 and 5 indicated "agree." This was done in order to make results more meaningful. Nine professionals agreed with the statement. Six professionals were neutral in their opinion, and one disagreed.

Of the sixteen professionals in the sample, twelve had themselves suggested, or had had a colleague suggest to the school that facilitated communication be used in the classroom. Three were not sure if any suggestion had been made. Five

professionals felt the school responded positively. Two felt the response was neutral, and two felt the response was negative. Five professionals were not sure what the response was, and one reported that a suggestion had not been made to the school. One professional did not respond to the question.

Fourteen professionals felt they had current clients who would benefit from using facilitated communication in the classroom. When professionals were asked for specific numbers of children actually using facilitated communication in the classroom and those who should be using it, many did not know, and therefore these questions had a poor response rate. One professional reported eleven clients were using facilitated communication in the classroom. Ten did not respond. Other numbers given were 0, 1, and 2. When asked the number of clients professionals felt **should** be using the technique in the classroom, answers ranged from 1 to 20. Seven professionals did not respond. Three said they knew of eight clients who should use facilitated communication in the classroom.

When asked how often professionals thought their clients could understand what was being said to them, 10 professionals said often. Five thought their clients could understand spoken language sometimes. Only one professional said always.

COMPARISONS BETWEEN PARENTS AND PROFESSIONALS

Children's Understanding of the Spoken Word

When parents were asked at what level they felt their children were understanding what was being said to them prior to the introduction of facilitated

communication, five felt they possessed a medium level of understanding. Four felt their children had a low level, while two felt their children possessed a high level of understanding.

The question was phrased slightly differently for professionals, but comparisons can still be made. Prior to the introduction of facilitated communication, ten professionals felt their clients understood what was being said to them often. Five felt their clients understood sometimes, while one believed clients understood always.

School Response to Facilitated Communication

Only eight parents responded to this question, as only eight parents had children enrolled in school. Six parents perceived the school response to be positive when it was suggested their children use facilitated communication in the classroom. One viewed the response as neutral, and one parent indicated that the school had not been approached yet.

Fifteen professionals responded to this question. Five professionals found the school response to be positive. Two found the response to be neutral, while two professionals found the school response to be negative. One professional had not approached the school, and five did not know what the school response was.

First Heard About Facilitated Communication

When parents were asked how they first heard about facilitated communication, five said through the media. Two reported they heard through their children's treatment center. The final four each mentioned the following respectively: autism

newsletters, journals and articles, a letter from a parent with a child with autism, and the Autism Society.

The majority of professionals (nine) reported they first heard about facilitated communication through the workplace. Three mentioned the media. The final four each mentioned the following respectively: parent of a client, colleagues, autism newsletters, and a parent of a former client.

Success as Facilitators

Of the nine parents responding, only four had acted as successful facilitators on at least one occasion. Success varied from children being able to respond by pointing to pictures and symbols to being able to respond by using single words.

Of the sixteen professionals responding, twelve had been successful as facilitators. Success was much more varied, ranging from children being able to use sentences to being able to point to pictures and symbols. Of the twelve professionals, five had been able to facilitate a child to respond in sentences.

The Authenticity of Facilitated Communication

Seven parents were either somewhat or very confident in the authenticity of facilitated communication. One parent was somewhat sceptical, and three were neutral.

Nine professionals were either somewhat or very confident in the authenticity of facilitated communication. Three were either somewhat or very sceptical, and four were neutral.

How to Increase Confidence Level

When asked what needed to happen in order for their confidence level to increase, four parents indicated that they were already confident in the authenticity of facilitated communication. Three reported that their children needed to do it. Two felt they needed to be successful facilitating with their children. One parent indicated a need to see the child communicate, while another parent indicated that more research needed to be done.

When professionals were asked the same question, nine felt there was a need for more research. Four professionals were confident in the authenticity of facilitated communication, and three reported that they needed to act as successful facilitators in order to believe.

Facilitated Communication and Integration

When parents were asked whether they agreed or disagreed with the idea that facilitated communication makes integration more possible, seven agreed. Four were neutral in their opinion.

When professionals were asked the same question, nine agreed, while six were neutral. One professional disagreed.

Theories of Autism

When parents were asked whether they agreed or disagreed with the statement that facilitated communication challenges existing theories that autism is a social-

cognitive-language disorder, seven agreed. Two were neutral in their opinion, while another two disagreed with the statement.

When professionals answered the same question, eleven agreed, while two disagreed with the statement. Three were neutral.

View of Children with Autism

When parents were asked whether they agreed or disagreed with the statement that facilitated communication challenges the view that children with autism are not able to understand or relate to the world around them, six agreed with this idea. Four were neutral, and one parent disagreed.

When professionals were asked the same question, an overwhelming fifteen agreed with this statement. One professional was neutral.

Children's Past Assessments

When parents were asked whether or not they found themselves questioning their children's past assessments in light of facilitated communication, four did not, and another four were neutral. Only three parents found themselves questioning their children's past assessments.

When professionals were asked the same question regarding their clients, ten found themselves questioning past assessments. Three professionals were neutral, while another three did not find themselves questioning clients' past assessments.

Relating to Children

When parents were asked if they found themselves relating to their children at a higher level than previously, four found themselves relating to their children at about the same level. Three were not sure, and two related to their children at a higher level. Only nine parents responded to this question.

When professionals were asked the same question regarding their clients, ten felt they were relating to clients at a higher level than previously. Four related to clients at about the same level, while two were not sure.

RELATIONSHIPS BETWEEN VARIABLES

Crosstabulations of parents and professionals were conducted on four questions: facilitated communication and integration, theories of autism, view of children, and childrens' past assessments. The capacity in which participants are involved with children with autism (parents or professionals) was treated as the independent variable. In order to do this, it was necessary to recode data in order to eliminate the "neutral" category. This was done by defining the neutral value, 3, as disagreeing with the statement. Therefore, the values, 1, 2, and 3 indicated "disagree," while values 4 and 5 indicated "agree."

Because of the small sample size, results will be interpreted according to Yates Correction. It is also wise to use this correction when at least one cell contains less than 5, which is the case in this study (Craft, 1990).

Facilitated Communication and Integration

According to the results of this first crosstab (Table 4.7) it is clear that no relationship exists between the two variables. When looking at the pattern before even looking at the statistics, one can see that there is no relationship. Among the parents, four did not believe that facilitated communication made integration more possible, where seven believed it did. Among professionals, seven did not believe facilitated communication made integration more possible, where nine did. Chi square equals 0, also indicating no relationship. Phi indicates a weak relationship, but according to the significance level, there is a 100 percent chance this is due to chance.

Table 4.7

Observed Frequencies and Percentages for Relationship to Child by School Integration and Facilitated Communication (N=27)

	Agree with Integration Possibilities?				Totals	
	<u>Yes</u>		<u>No</u>			
	Number	Percent	Number	Percent	Number	Percent
Parent	7	63.6	4	36.4	11	100.0
Professional	9	56.3	7	43.8	16	100.0
Totals	16		11		27	

$$\chi^2 = .00, df = 1, p = 1.0, v = .07$$

Theories of Autism

Table 4.8 also indicates no relationship between the two variables. Among parents, four did not believe facilitated communication challenged existing theories

about autism being a social-cognitive-language disorder, where seven did believe it did. Among professionals, five did not believe facilitated communication challenged existing theories, where eleven believed that it did. Chi square is 0, which also indicates no relationship. Phi indicates a weak relationship, but again according to the significance level there is a 100 percent chance this is due to chance.

Table 4.8

Observed Frequencies and Percentages for Relationship to Child by Autism Theories and Facilitated Communication (N=27)

	Facilitated Communication Challenges Autism Theories?					
	<u>Yes</u>		<u>No</u>		<u>Totals</u>	
	Number	Percent	Number	Percent	Number	Percent
Parent	7	63.6	4	36.4	11	100.0
Professional	11	68.8	5	31.3	16	100.0
Totals	18		9		27	

$$\chi^2 = .00, df = 1, p = 1.0, v = .05$$

View of Children with Autism

Table 4.9 does show a pattern. Five parents disagreed with the idea that facilitated communication challenged the view that children with autism are unable to understand and relate to the world around them, where six agreed with this statement. Only 1 professional disagreed with this statement and fifteen agreed. Chi square is 3.75, which is not significant at the .05 level (significance is .0528). It is significant at the .10 level. Phi is .463, which indicates a moderate to strong relationship.

Table 4.9

Observed Frequencies and Percentages for Relationship to Child by Limitations of Autism and Facilitated Communication (N=27)

	Facilitated Communication Challenges Limitations of Autism?					
	<u>Yes</u>		<u>No</u>		<u>Totals</u>	
	Number	Percent	Number	Percent	Number	Percent
Parent	6	54.5	5	45.5	11	100.0
Professional	15	93.8	1	6.3	16	100.0
Totals	21		6		27	

$$\chi^2 = 3.75, df = 1, p = .05, v = .46$$

Past Assessments of Children

Table 4.10 reveals a slight pattern, but according to the statistics, there is no relationship. Eight did not find themselves questioning their children's past assessments in light of facilitated communication, where three did. Six professionals did not find themselves questioning clients' past assessments, while ten did. Chi square is 1.98, indicating no significance. Phi is .346, which indicates a moderate relationship.

Table 4.10**Observed Frequencies and Percentages for Relationship to Child by Past Assessments of Children and Facilitated Communication (N=27)**

	Questioning Past Assessments?					
	<u>Yes</u>		<u>No</u>		<u>Totals</u>	
	Number	Percent	Number	Percent	Number	Percent
Parent	3	27.3	8	72.7	11	100.0
Professional	10	62.5	6	37.5	16	100.0
Totals	13		14		27	

$$\chi^2 = 1.98, df = 1, p = .16, v = .35$$

OTHER STUDY FINDINGS**Remarks From the Parents**

On the parent questionnaire (Appendix B), parents were invited to comment on the possibilities facilitated communication might offer their children. Comments were generally quite positive. One parent relayed a hope that the child will be given the chance to achieve his potential and to eventually become self-supporting. Another parent wrote "I am quite excited. I would love to know my son's true feelings after so many years of silence." Another parent hoped that involving her daughter in facilitated communication would allow the child to be able to be more clear about feelings, wants, and needs, and would make for less guess work on her part.

Some parents, although excited about the possibilities, also remained realistic as far as their children's autism was concerned. One parent wrote, "I am thrilled that my son will have a vehicle for communication. Although I don't expect it to change his autism." Another parent wrote, "I hope Jeff might be exposed to it but I'm not certain it will make a difference."

Remarks From the Professionals

On the professional questionnaire (Appendix D), professionals were invited to comment on the possibilities of facilitated communication and individuals with autism. A large proportion of professionals commented on how facilitated communication will change the way people view and treat individuals with autism. Many professionals commented on the need to address people with autism with respect and understanding. Professionals felt that by being more aware of the abilities of autistic individuals, we will heighten our expectations of them, as well as gain a more positive attitude towards them. One professional commented on increasing the self-esteem of people with autism. Others commented on gaining a greater level of independence, and having a more appropriate way to communicate feelings, wants, and needs.

Some professionals continued to be cautious about the impact of facilitated communication on individuals with autism, saying it appeared to have been successful with **some** people with autism. These professionals feel more research needs to be done, and a degree of scepticism must be maintained. Others have not been as optimistic about the futures of individuals with autism, since much depends on the

opportunities offered by the community. One professional wrote, "I don't feel that it will make the change in these individuals lives as it possibly could. These individuals have to learn to initiate the communication themselves rather than depend on another individual to initiate. Otherwise, they are still going to be "locked in their own world, unless given opportunities to be facilitated."

SUMMARY

In this chapter, the results of the study were discussed in terms of parent and child variables, and professional variables. Also discussed were comparisons between parental responses and professionals responses in certain areas. Other study findings include face-to-face interviews and the open-ended questions on the questionnaires.

CHAPTER 5

DISCUSSION, CONCLUSION, AND SUMMARY

INTRODUCTION

This chapter includes a discussion of the results of this study and how they are consistent and/or inconsistent with the literature, as well as possible explanations behind the responses of the study's participants. Future implications in policy and social work practice will be discussed and a summary of this study will also follow.

THE PARENTS AND CHILDREN

Demographics

The ages of the parents were fairly consistent with the ages of the children. Six children were under the age of ten, and five parents were in their twenties and thirties. It appears that there were no late births in this sample.

The literature says that autism occurs three to four times more frequently in males than females (Bristol, 1985; Charlop et al., 1991; Rosen, 1989). In the small sample involved in this study, nine of the eleven children were males, which is consistent with the overall occurrence of autism.

Family medical histories reported by parents include a number of disorders. Genetic research in the area of autism has linked its occurrence with cognitive and language disabilities (Piven et al., 1990), which have been reported by some parents in this study.

According to the literature parents often report that they began to notice difficulties with their children around the age of two (Ornitz & Ritvo, 1976; Prizant, 1988). In the sample all but one of the parents noticed difficulties when their children were between thirteen months and three years of age.

There are a number of reasons which help to explain the timing. According to developmental theory, between the ages of ten months and three years, children begin to explore their surroundings and themselves. The goal is to achieve a sense of autonomy and to see themselves as separate beings from their primary caregivers (Edward, Ruskin, & Turrini, 1981). Children with autism likely would not be displaying this behaviour, due to their impaired social abilities. It is within this time frame that children begin and progress in their speech (Liebert & Wicks-Nelson, 1981; Santrock & Yussen, 1984). Children with autism display profound deficits in language acquisition and use (Kostanareas, 1990; Jenson et al., 1985; Ornitz & Ritvo, 1976).

Children diagnosed as autistic are often diagnosed before or around three years of age (Bristol, 1985; Charlop et al., 1991; Rosen, 1989). In the sample this was often the case. In fact, according to the DSM-III-R (1987), one of the criteria for autism is diagnosis before the age of three years. However, there are allowances for "childhood onset autism" (DSM-III-R, 1987).

Although this is now a controversial area, the literature suggests that eighty percent of people with autism are mentally challenged and/or developmentally delayed to varying degrees (Moroz, 1989; Ritvo & Freeman, 1977; Charlop et al.,

1991; Schreibman, 1988; Mirenda & Schuler, 1988). Eighty-one percent of parents reported that their children had been assessed as functioning well under their chronological ages. Actual IQ levels were not obtained, as it was anticipated that many parents would not know this information.

Behavioural Characteristics

The data obtained in this area was generally consistent with the literature. All behaviours were present in at least two children in the sample. There was a high (six and above) incidence of classic autistic behaviours. In order for children to be diagnosed as autistic there needs to be a presence of certain stereotypical behaviours (DSM-III-R, 1987).

The literature suggests that children with autism process and store stimuli differently than other children. Children with autism tend to store data in chunks, often referred to as "gestalt processing." Gestalt processing is said to explain why children with autism excel in visio-spatial tasks such as puzzles and arithmetic because of the non-transient nature of them (Prizant & Schuler, 1987). Some parents in the sample reported their children were good at puzzles. One parent reported his child excelled in spelling when using facilitated communication. Whether this can be classified as an unusual skill or normal ability depends largely on where one stands on the theory behind autism.

Proponents of facilitated communication would contend that children with autism have learned on their own and until facilitated communication, have never had an opportunity to exhibit their abilities. Sceptics would argue that the spelling

abilities of some children with autism are due to them being "hypergraphia," meaning their writing abilities exceed their supposed intellect. "Hyperlexia" refers to a child's word recognition skills exceeding his/her supposed intellect (Whitehouse & Harris, 1984, as cited by Biklen et al., 1992). Schopler wrote that some autistic clients may excel with computers and are precocious readers, but this is only a handful of clients (Schopler, 1992).

All parents reported that their children exhibited fearful responses to certain people and animals. The majority of parents classified these fears as extreme. This could be due to a number of factors. It may be a result of sensory disturbances often exhibited by children with autism. When they are in a hypersensitive state they tend to have exaggerated responses to the environment. Sudden confrontations with people may elicit extremely fearful responses (Ornitz & Ritvo, 1976). Children with autism also can become upset if rituals are disrupted or if something changes in their environment (STA, 1992). The entrance of people or animals into their environment can be seen as a disruption.

The fact that just less than half the sample of children exhibited poor coordination highlights the mobility problems often seen in children with autism. Eye-hand coordination is often poor (Biklen & Schubert, 1991; Biklen et al., 1992; Crossley, 1991; Crossley, 1992; Crossley & Remington-Gurney, 1992). The same amount of children in the sample exhibited odd postures, which is also common in children with autism (STA, 1992). The data collected on the fine skill ability of the children in the sample is quite consistent with the literature. Eighty-one percent

were viewed as awkward by their parents. Proponents of facilitated communication argue that facilitation is necessary due to children's fine skill difficulties, such as isolating their index finger. Following through with intended movement is difficult due to coordination problems, and complex movements are difficult (Biklen & Schubert, 1991; Biklen, 1992; Biklen et al., 1992; Crossley, 1992; Crossley & Remington-Gurney, 1992).

Communication

Considering the fact that most parents reported that their children were assessed as functioning well below their chronological age levels, it should not be too surprising that only two saw their children as having a high level of understanding of the spoken word. Parents may have been told by professionals not to expect too much from their children and that there is no "cure" for autism, nor are their children going to "grow out of it."

According to the results, most of the children in the sample began to use words within the normal range, although one never used words. Many children with autism are totally nonverbal (Ornitz & Ritvo, 1976; Biklen et al., 1991). It has been shown that about one half of children with autism fail to acquire speech by adolescence (Mesibov, 1983). Although it would appear that most children in the sample began using speech within the normal range, they did not progress, which is typical of the autistic syndrome. It is also not uncommon for children with autism to stop speaking after acquiring speech (Biklen et al., 1991). This phenomenon

occurred in the sample of children, although two did begin to speak again after a period of silence.

When parents were asked what types of verbal communication their children typically exhibited there appeared to be some inconsistency with previous responses. This could be due to parents' interpretations of verbal communication. Children who do verbalize may do so minimally and therefore parents do not consider this to be verbal communication. The fact that none of the children had all original speech is very consistent with the literature (Ornitz & Ritvo, 1976; Rutter, 1978; Jenson et al., 1985; Biklen et al., 1991).

When questioned about pronoun reversal four parents reported their children were non-verbal, which is inconsistent with the previous question. This could be explained by the fact that when asked about verbal communication a parent reported the child used single words or word approximations. Due to the nature of the child's verbal communication, and the fact that pronouns did not come into play in the child's repertoire, the parent may have reported the child had no verbal communication. Children with autism often use pronouns incorrectly (Jenson et al., 1985; Ornitz & Ritvo, 1976; Biklen et al., 1991).

The literature suggests that for children for whom facilitated communication has been successful, past communication techniques have had limited success (Biklen & Schubert, 1991; Biklen et al., 1991; Biklen et al., 1992). Although it is too soon to tell in this sample just how successful facilitated communication will be for these children, previous techniques have had limited success.

Education

There has been speculation by proponents of facilitated communication that the integration of children with autism into mainstream schools will increase as the technique becomes more widespread (Remington-Gurney & Crossley, 1990). In the study conducted by this researcher most children who were in school were still in special education classes, although it would appear that the schools were open to the possibilities of integration. Remington-Gurney and Crossley (1990) suggest that education professionals need to be trained in facilitated communication and willing to try it in order for integration to be successful. Biklen and Schubert (1991) outlined a number of considerations regarding facilitated communication of which need to be taken heed of when attempting integration of children with autism. These considerations will be outlined later in this chapter. An important point to be made is that schools must have access to the resources necessary for facilitated communication to be successful. If these resources are not available then the result is "maindumping," as opposed to "mainstreaming" (Biklen & Schubert, 1991; Remington-Gurney & Crossley, 1990). The fact that only three children in the sample were in integrated classrooms and only one was using facilitated communication in the classroom may be indicative of a lack of resources and training on the part of education facilities.

The majority of parents believe that facilitated communication makes integration of children with autism

more successful. This is consistent with a study conducted in Melbourne. Parents in that study viewed integration more positively because of facilitated communication (Remington-Gurney & Crossley, 1990).

Facilitated Communication

It is likely that the media blitz surrounding facilitated communication has been responsible for parents becoming aware of the subject. Facilitated communication was being practiced in a number of places, such as Melbourne, Toronto, and Syracuse, before reaching the treatment centre from where this sample was drawn. Most parents in the sample first heard about it through the media. Indeed, critics of facilitated communication cite the media blitz as being partly responsible for the promotion of facilitated communication in North America (Schopler, 1992; Prior & Cummins, 1992).

The children who had tried facilitated communication were all successful to varying degrees. Proponents of facilitated communication report that success goes hand in hand with a positive relationship between the communicator and facilitator, and with the length of time spent with the technique and/or with the facilitator. A series of progressive exercises are introduced to the children as they and the facilitators become more familiar with the technique. The time taken to go through these exercises varies from child to child and from facilitator to facilitator (Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991; Biklen, 1992; Biklen et al., 1992; Crossley, 1991; Remington-Gurney & Crossley, 1990; Donnellan et al., 1992).

It would have been helpful if this researcher had asked how long the children had been involved with facilitated communication. It is entirely possible that some parents may not be aware that their children are using the technique. Some even reported that they were not sure.

The fact that most parents want their children involved with facilitated communication could be subject to a number of interpretations. Critics fear that parents are expecting that their children need only be exposed to facilitated communication and they will be able to have normal conversations (Calculator, 1991; Prior & Cummins, 1992; Schopler, 1992). However, later in the questionnaire when asked how they feel about facilitated communication and their children, a number of parents stated that they do not expect it to change their children's autism. Parents may just want their children to experience all the opportunities available to them. Where critics speak of the ethical ramifications of exposing children to an empirically unsound technique, others believe that not allowing children the opportunity to try facilitated communication is more serious (Donnellan et al., 1992).

The fact that all the parents had tried facilitating with their children or wanted to try supports the notion that parents need to be involved with the treatment and education of children with autism. This makes the child's whole treatment environment much more consistent, which is documented to be highly beneficial (Harris, 1984; Moroz, 1989).

When asked if they had observed their children communicating through facilitated communication only three parents responded "yes" even though four

parents reported earlier that they have been successful as facilitators with their children. This could be explained through how parents may be interpreting the question. Only ten parents responded to the observation question, therefore the parent who did not may have found the question to be nonapplicable since she had already said she had facilitated with her child.

The agency from where this sample was taken is very much pro-facilitated communication, and therefore the fact that the majority of parents were confident to varying degrees of the authenticity of facilitated communication could be viewed as biased. In an article by Prior and Cummins, a mother is mentioned who although having great reservations about the authenticity of facilitated communication, continued to be involved with it because she did not want to alienate the agency involved (Prior & Cummins, 1992).

It appears that the parents in this sample are not as concerned with the empirical research behind facilitated communication as they are with how it affects them and their children. For this reason most only needed to see their children facilitating or have the opportunity to facilitate with their children in order to be more confident of the authenticity of facilitated communication. The four who indicated they were confident and needed no further proof were likely those parents who had successfully facilitated with their children. Many proponents of facilitated communication indicate that in order for one to truly believe in its authenticity one must successfully act as a facilitator.

Only about half of the parents indicated they felt highly supported in their positions regarding facilitated communication. This could be indicative of the controversy and scepticism surrounding the technique. It can be a highly personal issue for many parents of children with autism. The fact that parent support groups are named most often as sources of support highlights the importance of these types of groups for parents of disabled children. Many parents receive emotional support and are able to share experiences with others in the same situation. It keeps families from feeling isolated (Prizant, 1988; Wintersteen, 1988).

The fact that the majority of parents indicated that they felt facilitated communication challenges theories which suggest that autism is a social-cognitive-language disorder could also indicate a biased sample. Critics of facilitated communication, however, feel that the technique has been blindly adopted by parents because they as a group are highly vulnerable to "miracle breakthroughs" which may lead their children to normalcy (Prior & Cummins, 1992). At the same time, the alleged observation of abilities of children with autism which appear through facilitated communication is consistent with a seemingly universal feeling from professionals and lay persons that children with autism have capabilities beyond their performance level (McLean, 1992). The two neutral responses may be indicative of parents not being sure of or not understanding the question.

Generally parents appear to agree that facilitated communication changes the way they view their children. The four neutral responses, as mentioned above, could indicate that parents were not sure of or did not understand the question. The fact

that only three parents indicated that they now find themselves questioning their children's past assessments is open to interpretation. The way parents responded depends a lot on what these past assessments were and whether or not parents agreed with them in the first place. One parent wrote right on the questionnaire that he never believed the assessment in the first place. Again, whether or not facilitated communication has changed the way parents relate to their children depends on what level parents initially related to their children. If parents already related to their children at a high level, there likely would be no change. This is also tied in with whether parents believed the past assessments.

Among the sample facilitated communication has not really affected how much parents worry about their children. This could be due to parents being realistic about autism. As mentioned in the previous chapter many parents indicated via open-ended questions that they knew facilitated communication would not change their children's autism. They also may be aware that facilitated communication can only be helpful if children are given ample opportunity to use it (Crossley, 1992). This may also reflect early attempts at facilitated communication; the children are just starting to use it. Parents may be reserving their optimism; we do not know how often they have gotten their hopes up in the past.

Concerns

In a number of studies on parental stress it has been documented that the stress of raising a handicapped child is significantly higher than raising a non-handicapped child (Noh, Dumas, Wolfe & Fishman, 1989; Donovan, 1988). The fact

that many parents found their children's behaviours to be cause for concern is really not surprising. Stereotypical and/or aggressive behaviours can make outings, schooling, and family time difficult (Moroz, 1989; DeMyer et al., 1983; Marcus, 1977; Roberts, 1984).

Although not addressed in this study, marital discord can become an issue in families with a member with autism (Harris, 1984). The demands of the child diverts attention from the marriage and all energy goes into caring for the child (Harris, 1984). In a study by DeMyer et al. (1983), when describing stresses of parents with children with autism, marital discord was frequently mentioned. In the twenty-three families studied there were six divorces, and five confirmed that the strain of raising a child with autism was a contributing factor (DeMyer et al., 1983). Planning becomes difficult, and parents may fear that due to their bizarre behaviours these children will never be self-sufficient (Wing, 1980; Marcus, 1977).

It has been written many times in the literature that communication and social skills is a big area of concern for many parents (Prizant, 1988; Kostantareas, 1990; Harris, 1984), and this continues to be the case in this study. In the psychoeducational approach to family therapy with families of autistic children, working with the family to enhance or encourage communication with their children is stressed (Kostantareas, 1990; Moroz, 1989). A lack of social skills are also linked with the stereotypical behaviours often exhibited. It is likely that facilitated communication is an area of great interest to parents for this exact reason. One parent wrote that

just being able to know her daughters thoughts and needs, without having to guess, would be great.

Safety issues are likely tied to the tendency for children with autism to ignore their environment, therefore ignoring traffic. Aggressiveness and self-abuse also come into play. Parents may also fear their children being taken advantage of in one way or another. The father of a teenaged girl this researcher used to work with had a real fear of her being sexually attacked. All but one parent indicated safety to be a concern. Financial issues are also very real for parents, as treatment can be extremely expensive. The Canon Communicator, used in facilitated communication, is several hundred dollars. This researcher's own experience has been that many parents need to rely on government child welfare agencies to get their children treatment and programs due to large costs.

The fact that four parents indicated that health issues were a concern could be explained by the fact that the child sample consisted of four adolescents and young adults. It is not uncommon for adolescents with autism to develop seizures (Dalldorf, 1983). The seizure activity would then need to be controlled through medication, which could have a number of side effects. Although aggressive behaviour actually reduces in adolescence, the size and strength of the adolescent may make the aggressive behaviour seem worse. Aggressive behaviours may require fairly strong medication, which again can have a number of side effects (Dalldorf, 1983).

Among the children in the sample, three were in a group/treatment home setting. Five parents indicated that they were concerned about residence, as putting children into residential treatment can be quite stressful. Parents may feel guilty. Other parents may be at the agonizing stage of having to consider residential treatment for their children. Just deciding on programs or even getting through a waiting list can be stressful. It has been this researcher's experience that residential treatment settings for people with autism are often hard to get into and waiting lists are long.

The fact that some of the children in the sample are clearly adults can also be a concern for parents, who may be worrying about where their children will live and who will take care of them (Wing, 1980; Marcus, 1977). The whole issue of the future also comes into play here. One parent indicated "the group home" as an area of concern and this has been interpreted as the same as "residence." The parent, however, may have concerns about the program specifically, and whether or not it is meeting the child's needs. Parents worrying about "residence" may be concerned about the same things.

THE PROFESSIONALS

Demographics

It would seem likely that child care workers may have felt the most qualified to answer the questionnaire since they spend the most time with the children. They likely would have more of an opportunity to attempt facilitated communication than

other employees of the agency. Proportionately there may also be more child care workers than other professionals. Higher level professionals may not have the same contact with the children, and therefore, may have felt they could not attribute much to the study. Another possibility is other professionals may not have had the time, or just did not receive the questionnaire for whatever reason.

In my experience with residential care, child care workers are typically quite young. In this study since most professionals were child care workers it does not surprise this researcher that most fell in the 20-29 age range, with only 1-5 years experience. It would be unlikely that people in their twenties would have much more experience, especially after post-secondary education. These days most child care workers are required to have college diplomas in child care. Although the majority of professionals were female this is not to suggest that child care is a female-dominated profession. Gender may be more related to the type of children being cared for. It has been this researcher's experience that male child care workers are more represented in the hard to serve adolescent homes, such as young offender services. Again, this is just conjecture.

Facilitated Communication

It is not surprising that most professionals heard about facilitated communication through the workplace, especially if they worked there prior to the media blitz. The agency through which this sample was taken from was basically responsible for bringing facilitated communication to the region, as the speech pathologist went to Australia to see Rosemary Crossley.

The majority of professionals were confident in the authenticity of facilitated communication to varying degrees. All of the professionals, except one, had enjoyed success with facilitated communication in varying degrees, and therefore it is likely they would be somewhat confident in its authenticity. Those who are still questioning may be cautious because of limited experience.

Professionals are likely to be more research-oriented and therefore would suggest more research be done in order to increase their confidence in the technique. Most professionals were confident in the authenticity of facilitated communication, therefore many did not require more exposure to it personally.

Since the agency these professionals were employed at is "pro-facilitated communication," it is not a big surprise that only two would view support as low. However, one must wonder where these people are coming from if they see support for facilitated communication as low, as when this researcher was there support appeared very high. The neutral category also tends to get chosen when people are not sure.

All the professionals who had already learned to facilitate were child care workers, including supervisors. Of the two who expressed an interest in learning, one was a child care worker, and the other was a social worker. An interesting fact is the two who were not sure if they wanted to learn were an assessment worker and a psychologist assistant. A major source of conflict in the area of autism are the psychological instruments used to measure children's functioning level. Proponents of facilitated communication argue that these instruments are limited in expression,

as many people with autism would be at a disadvantage due to expressive difficulties (Crossley, 1992). Sceptics tend to use these assessment results as arguments against autistic children's abilities to communicate via facilitated communication. Furthermore, these instruments are often used as a way to determine whether or not a person is capable of responding in ways documented through facilitated communication (Crossley, 1992). It is also interesting to note that the assessment worker was neutral as to the authenticity of facilitated communication, and the psychological assistant was somewhat sceptical. This professional had not even observed a child communicating through facilitated communication. One must wonder if this person was brushing off the whole possibility of facilitated communication.

The responses regarding theories surrounding the autistic syndrome is not surprising considering the push for facilitated communication within the agency. One professional indicated a neutral position, however she wrote beside the question that she did not really understand the question. There is always a danger in people responding neutrally when not understanding the question. The fact that all but one professional indicated that facilitated communication has changed the way they view children with autism is consistent with their open-ended remarks at the end of the questionnaire. Many reported the need to see people with autism as individuals with potential, demanding of respect. Some indicated that facilitated communication has reminded them that people with handicaps deserve to be treated with dignity.

Responses to whether professionals thought facilitated communication has led to them to question their clients' past assessments may very well depend on what

these assessments were and whether professionals accepted these assessments. The three who disagreed could have views of clients that are not swayed by facilitated communication; perhaps low assessments have never been accepted, or the professional has not decided on what facilitated communication means. Neutral responses may also be reflecting professionals not being sure.

Because so many professionals in the sample were involved with facilitated communication it is not surprising that a large number have changed the way they relate to their clients. Facilitated communication likely has reminded them to view clients with respect and they are more careful not to talk down to them. As mentioned in Chapter 4, many professionals stated the need to treat people with autism with respect. One professional (the psychological assistant) stated that she always related to clients on a high level, and that facilitated communication had nothing to do with it.

The overall level of optimism regarding the independence of clients with autism is positive. Some professionals commented that much of the independence achieved by people with autism depended on opportunities given to them, not the technique itself. This is consistent with the literature, in that facilitated communication may be the vehicle by which people with autism can begin to assert themselves and communicate competencies (Crossley, 1992).

Education

Because the future ramifications of facilitated communication continues to be unknown, there was a lot of uncertainty among professionals as to whether facilitated

communication will make classroom integration easier. The impact facilitated communication will have on the education system is not known because the technique is so new. A further complication is the controversy among experts as to whether or not facilitated communication is even valid. Schools may be wary about putting programming and education dollars into a technique surrounded by such controversy. Among the sample most did agree that integration and facilitated communication may go hand in hand; however, six gave neutral responses, which could be interpreted as "uncertain."

Yet it would also appear that the professionals in this sample have hopes of what facilitated communication could mean to children's education programs, as 75 percent pursued suggestions of using the technique in the classroom. As suggested above, however, schools appeared somewhat hesitant to this suggestion as only five professionals reported a positive response from schools. Schopler (1992) has criticized facilitated communication for suggesting that children with autism are not mentally handicapped at all. It may be very difficult for education professionals to "risk" the special education programs already in place for these children, and put money into equipment and manpower in order to incorporate facilitated communication into schools.

The literature outlines a number of steps which need to be taken in order for facilitated communication to be incorporated into classrooms, which would be time-consuming and expensive (Remington-Gurney & Crossley, 1990; Biklen & Schubert, 1991). Therefore, many schools may require more "proof" as to the authenticity of

the technique in order to get proper funding. One child care worker this researcher interviewed wonders how much faster things would have moved along if this "discovery" was made higher up in the scheme of things. A problem continues in that although in practice facilitated communication appears to work, there continues to be no theoretical backup, thus making academics sceptic as to its validity (Silliman, 1992).

The controversy of facilitated communication continues to be seen in the fact that although fourteen professionals could think of clients who would benefit from facilitated communication in the classroom, only five knew of clients using facilitated communication in the classroom. However, it is entirely possible that staff would not be sure of what is happening with their clients in the classroom. This could be a sign for better communication being needed between caregivers and schools.

PARENTS AND PROFESSIONALS

Children's Understanding of the Spoken Word

Parents tended to see their children as more limited. Professionals seemed to see children as having a greater capacity to understand. This researcher is not sure why this is, as it has been this researcher's experience that parents tended to be less realistic about their children and saw progress in areas where there was not any. Responses may depend on the ages of children and the degree of autism. Also, professionals may be more sensitised to the need to view handicapped clients in a more positive light and concentrate on abilities rather than disabilities.

School Response to Facilitated Communication

Relatively speaking, it would appear that parents experienced a more positive response from the school than professionals. Five professionals did not know the schools' response. Also, with the parent questionnaire, the way the question is worded, the suggestion could have also been made by a professional, which make it difficult to make direct comparisons between the groups. Much also depends on how the respondent defines positive and negative responses.

First Heard About Facilitated Communication

The results of this question make a lot of sense. There has been a lot of media coverage on facilitated communication and parents are going to be drawn to shows such as 20/20 and W5, which have aired specials on facilitated communication. Considering the agency is pro-facilitated communication it would stand to reason that professionals would hear about the technique through work.

Success as Facilitators

It is not surprising that more professionals reported success as facilitators. Only four of the parents had even tried, whereas twelve professionals reported success. Since facilitated communication is the main thrust of the agency from where this sample was taken, it would only be fitting that the professionals would have some proficiency with the technique. It is interesting to note that all but one of the professionals who reported success as facilitators were child care workers. One was

an assessment worker. This could be due to the fact that the child care workers spend the most time with these children, and therefore had the most opportunity.

Success as facilitators for parents was generally confined to children being able to point to pictures or symbols, whereas professionals tended to report children being able to communicate through words and sentences. The literature suggests that there have been instances where parents have not been successful as facilitators (Biklen, 1990; Biklen et al., 1991; Biklen et al., 1991; Prior & Cummins, 1992). Reasons for this are not clear. Some believe that children do not feel their parents are truly believing in facilitated communication. Results of this study suggest that the parents in this sample tended to be more sceptical of facilitated communication than the professionals. It may be that the parent/child relationship adds too much pressure for children to be successful. Perhaps children wish to maintain the "status quo" by not communicating with their parents. Sceptics argue that with all the emphasis placed on trust, children not being able to communicate with their parents does not make sense (Prior & Cummins, 1992).

The parents in this study had only begun to learn how to facilitate, and likely they were in the early stages of learning the technique. It is also important to note that professionals who report being able to communicate with their clients through words and sentences may not be experiencing this degree of success with all their clients. As mentioned in the literature review, success at facilitated communication varies among professionals and children alike, and the nature of the relationship between them, and the amount of practice time.

The Authenticity of Facilitated Communication

There was not much difference between parents and professionals in their opinions regarding this area. There was a higher percentage of professionals who were sceptical. Professionals, which will be seen under the next section, tended to be more research-oriented. Therefore, professionals may be more inclined to scepticism because of the lack of what some call "conclusive evidence" that facilitated communication works.

How to Increase Confidence Level

Again, it is not surprising that professionals would be more concerned with continued research in the area of facilitated communication in order to feel more confident in its authenticity. Using well-researched intervention techniques would be in a professional's best interests. Indeed this is the thrust of sceptics arguments; that it is unethical for professionals to introduce facilitated communication to their clients in the absence of what sceptics would call "empirically sound validity" (Prior & Cummins, 1992; Schopler, 1992).

On the other hand, parents would be more concerned as to how their children responded to new techniques being introduced. This is indeed the case in this study. Parents indicated that either their children needed to do it, they as parents needed to be able to facilitate with their children, or they needed only to watch their children communicate through facilitated communication. The four parents who were already confident in the authenticity of facilitated communication were those parents who had been successful as facilitators.

It is interesting to note that although many parents and professionals stated to be somewhat or very confident in the authenticity of facilitated communication previously, quite a few of these people still felt they needed more evidence of the technique's authenticity. It could be that with all the controversy surrounding facilitated communication, people are reluctant to say they are convinced. Also, among sceptics are professionals who are revered in the area of autism, such as Eric Schopler. This would only serve to make people more inclined to question. One child care worker felt that if support for facilitated communication filtered down instead of up, we would not have the controversy we are experiencing now.

Facilitated Communication and Integration

Opinions of parents and professionals tended to be similar and quite close percentage-wise. The full impact of facilitated communication on the education system is not yet known, which would explain some people's neutrality in this area. As mentioned in the literature review the pairing of facilitated communication and education has been written about extensively. Doug Biklen, thought of as the North American spokesperson for facilitated communication, is an education specialist. Rosemary Crossley is also an education specialist. Sceptics have stated their reservations about combining facilitated communication and education. They have also stated that by suggesting the children with autism are not intellectually delayed, special education programs are put in jeopardy (Prior & Cummins, 1992). At the same time, the need to equip school programs with the necessary personnel and devices in order to make facilitated communication a vehicle by which children with

autism can learn, could keep many programs from being implemented due to funding and personnel problems.

Theories of Autism

Both parents and professionals held similar opinions in this area. The fact of the matter is that whether or not one chooses to be pro-facilitated communication or not, it is hard to argue that the idea of facilitated communication does not challenge theories surround the etiology and manifestation of autism. In fact it is for this very reason why facilitated communication is surrounded by such controversy. Neutral responses could simply imply that people do not understand these theories or are not sure why facilitated communication appears to work. Sceptics may not see facilitated communication as challenging theories of autism simply because they do not believe children are communicating independently.

View of Children with Autism

Parents tended to be more cautious in this area. This could be a function of protecting themselves from getting their hopes up. Just over half agreed that facilitated communication challenged the view that their children were not able to relate or understand the world around them, however a substantial percentage were neutral and one disagreed. It may have taken parents years to come to terms with their children's disabilities, and to look at the possibility that their children may not be as handicapped as once thought may be a scary prospect for parents. Also, there may be strong elements of guilt for letting go of optimism.

On the other hand, no professionals disagreed with this. Only one was neutral. Perhaps due to professional distancing it is easier for professionals to consider the idea of children with autism being more aware of their surroundings. Professionals may also be more educated in the research and theories behind autism and facilitated communication, therefore feeling better qualified to answer the question. Again, as suggested in the literature, facilitated communication supports the fast-held idea by professionals that there is more to autism than meets the eye (McLean, 1992).

Children's Past Assessments

Professionals tended to question children's past assessments in light of facilitated communication, where parents did not as much. As mentioned earlier in this chapter, responses very much depended on what these past assessments were and if participants agreed with these assessments. Some parents may not know what the assessments mean exactly. One parent told this researcher that she had a hard time getting any assessments done on her child or acquiring an indication of what her child's functioning level was. The fact that only four parents were able to say their children had been using facilitated communication may have a lot to do with how parents responded to this question. If more had been exposed to this technique at the time of this study, this question could have been answered a lot differently.

Since more professionals had been exposed to successful sessions with children, it is not surprising that more would be inclined to question past assessments. Others may not be sure because they may have not been sure of what past

assessments children had received. Also, some professionals may purposely be ignoring children's past assessments and just concentrating on how they respond to facilitated communication. In our profession, workers are often encouraged to not rely on past assessments in order to form our own opinions, and to concentrate on what clients are presenting to us at the time.

Relating to Children

Again, professionals tended to change the way they related to their clients in light of facilitated communication. Professionals also relayed this in the open-ended section of the questionnaire as a possible positive outcome of facilitated communication. Parents tended to be more reserved. Responses very much depended on how parents related to their children in the first place.

It may also be hard for people to be sure of how they are relating to children now in comparison to before facilitated communication. Also, some parents may not have had enough exposure to facilitated communication for it to have any effect on how they relate to their children. Since facilitated communication is a major thrust of intervention within the agency it is not surprising that more professionals would be more aware of how they are relating to their clients. Also, some workers were so new to the agency that facilitated communication has been part of the program that they have nothing to compare to.

RELATIONSHIPS BETWEEN VARIABLES

The results of these tables may very well be the function of small sample sizes. The fact that cells often had less than five frequencies would leave much to chance. In those instances where Chi Square was 0, it is likely that there would be no relationship regardless of the size of sample sizes.

However, in those tables where a pattern appears to exist with minimal to moderate statistical support, larger sample sizes may yield stronger results. The latter two tables suggest that further research in this area may be beneficial as relationships between variables are suggested. More indepth and concentrated studies may reveal a number of extraneous variables, which when controlled for, may heighten relationships between these variables, or even reduce relationships. Further studies may highlight relationships obscured by mitigating factors in participants' situations.

FUTURE DIRECTIONS IN RESEARCH

Effectiveness Versus Efficacy

The debate between followers and sceptics of facilitated communication continues to involve demanding proof that it indeed works. What needs to be pursued is an understanding of how facilitated communication works as a communication process and move away from its value as an instructional technique. In other words, we are getting too focused on its effectiveness, and this in turn leads to an emphasis on the collection of isolated data "whose meanings remain enigmatic

because they are not logically connected to an explanatory framework" (Kaval, 1990, as cited by Silliman, 1992, p. 65).

Facilitated communication research is not premised on a model of language-learning-literacy connections. The very term implies that oral language and literacy learning are interconnected through listening, speaking, reading, writing, and spelling. Augmentative approaches to communication, which are not new to the field of autism, are based on the above philosophy in which the oral mechanism is bypassed, yet still integrates cognitive, interactional, and functional domains (Mirenda & Schuler, 1988; Prizant & Schuler, 1987; Silliman, 1992).

Although at first facilitated communication may appear highly directive (structured work), there still comes a time when children of varying abilities progress from set work to becoming active participants in conversations. This has proven to be difficult for sceptics to accept, because it is not understood why this happens (Silliman, 1992).

Perhaps one of the biggest criticisms in the qualitative studies which have been presented by Biklen and his colleagues is the lack of information regarding participants and their backgrounds (Calculator, 1992b; Sillman, 1992). For example, Biklen et al. (1992) use the terms "effective" and "ineffective" to describe the communication characteristics of participants prior to facilitated communication. Ineffective communication is simply defined as no verbal speech, or only echoed speech (Biklen et al., 1992). This leaves a wide variation between children and their abilities. Silliman sees a lack of clarity in how children's words, phrases, sentences,

open-ended conversations, ability to read, and literacy are interpreted (Silliman, 1992).

Because there is very little information provided on each participant's functioning level (i.e., severity of autism, education background), we are not really clear of how each child differs from the other. For this reason it makes it harder to accept the global apraxia hypothesis (Silliman, 1992).

Silliman suggest clearer definitions be used in order to make studies more sound. By describing the communication behaviours of each child more precisely readers will have a better idea of how facilitated communication has operated with each child (Silliman, 1992).

The fact that most qualitative studies rely on observation as a means of data collection can leave it open to criticism. Direct observation has been compared to "a series of mental lenses that yield varying pictures of communication processes" (Silliman & Wilkinson, 1992, as cited by Silliman, 1992, p. 66). What one observes often depends on what one is looking for. The goals of a study often guide the selection of observational tools, their focus, and the units chosen for interpreting behaviours. The data in Biklen's studies is presented in the form of narrative accounts of particular children's communication, which serves to describe a group, and verbatim transcripts of communication. It is therefore not clear how each child was observed and if individual investigators were working in adherence to the same goals (Silliman, 1992).

Supporters of facilitated communication will continue to argue that the technique works on the basis of a relatively intact language-processing capacity. Sceptics will continue to demand hard empirical evidence for the intactness of phonological processing in children with autism. In order to gain this evidence sceptics will ask for theoretical soundness of language-learning-literacy connections, clearer definitions, and more detail concerning actual observational techniques used in inferring these connections (Silliman, 1992).

Ehri (1989) and Juel (1990) propose that invented spellings "reflect precursory metalinguistic attempts to analyse possible linguistic connections among phonologic, lexical, and alphabetic systems" (Silliman, 1992, pp. 67-68). Therefore, steps need to be taken to reveal in greater detail the systematic mapping of spelling strategies across these three systems. This would be the first step toward understanding facilitated communication, thus authenticating it. It would also lead us to begin to revise current thinking where autism is concerned (Silliman, 1992).

Future research is not only warranted in the area of cognitive impairment and autism, but also into the nature of literacy and the neurological links between speech and hand function (Losche, 1990, as cited by Crossley, 1992).

McLean contends that some of our most successful behavioural techniques have never really been clarified to everyone's satisfaction. He further contends that we as professionals demand a procedure be objectively tested to prove its success in changing behaviours before we look for explanations for success (McLean, 1992).

Post-traumatic Stress Disorder

Donnellan et al. (1992) has noticed that the autistic behaviours of children involved with facilitated communication have not subsided. In some cases they have gotten worse. Donnellan et al cite Majure (1992) when hypothesizing that perhaps children with autism who are exposed to facilitated communication may be reacting to finally being able to express their frustrations. He likens this to a type of traumatic stress as a result of experiencing things so alien from what these children are accustomed to. The deterioration of behaviours, although not overly representative of children in this population who have been exposed to facilitated communication, may be indicative of the actual technique itself being a traumatic experience (Donnellan et al., 1992).

McCann and Pearlman (1990) write that it is not the problems we are used to that disturb us, but rather those cognitive experiences that are foreign to our own history and cognitive schemas (Donnellan et al., 1992). If this be the case, is there little wonder that many of these children do require emotional support when being exposed to facilitated communication?

The Difficulty with Validation

Donnellan et al. consider the ramifications if facilitated communication is exactly the ventriloquism phenomenon Schopler (1992) proposes. Why would these children continue to allow facilitators to guide them through these exercises day after day? This would also call into question current beliefs about the autistic syndrome (Donnellan et al., 1992).

Until communicators gain independence, acquiring empirical validity is going to continue to be difficult. For this reason, we need to continue to retain some degree of scepticism for legal and ethical reasons. Perhaps techniques used to validate facilitated communication may need to be altered. It is arguable that the whole testing situation undermines the performances of participants. It may also be an unrealistic demand that empirical validity be established too early on after the initial introduction of a technique (Donnellan et al., 1992).

The difficulties which have been encountered when trying to validate independent communication could obviously be avoided if children were not given the opportunity to use communication aids until they could demonstrate an ability to use them on their own. However, then one must question as to whether it is justified to withhold communication opportunities for an indefinite period of time because a person needs physical assistance accessing these communication aids. This could be particularly harmful for older children whose educational future may suffer as a result (Crossley, 1992).

Abuse Allegations and Facilitated Communication

The vulnerability of the developmentally handicapped to abuse has been well documented. Baladerian (1991) reports that estimates of sexual abuse in developmentally handicapped girls under 18 range from 39 percent to 83 percent. In boys under 18 with developmental handicaps, estimates range from 16 percent to 32 percent. In the general population these figures are 25 percent and 20 percent

respectively (Howlin, 1994; Starr, 1994). Therefore, it is safe to say that the fear of abuse in the disabled population is very real.

To date, there have been numerous allegations of abuse, namely sexual abuse, which have been made by children while using facilitated communication; often naming parents as the perpetrators (Howlin, 1994; Starr, 1994;). As a result, there is a "minefield" of lawsuits culminating in the United States by parents who have been named as alleged abusers (Jones, 1994). What has often occurred in these cases is that an investigation is launched based on the allegation alone. As a result, children have been removed from the home, or parents have been refused access to their child in a group home. This has left parents feeling not only stigmatized and unjustly humiliated, but also facing large legal bills. Also, with the backlog of cases going through the court system, many of these cases have dragged on for months, keeping parents and children separated (Jones, 1994; Starr, 1994). There is even a support group solely for these families (Autism Research Review International, 1993, as cited by Starr, 1993). It is important to note that in all cases of abuse allegations, no one has been convicted as of this date (Starr, 1994).

In a recent case in Aurora, Ontario, a father was finally reunited with his 20-year-old son after the Crown failed to collect enough evidence. The father had been kept from his son for over a year. Subsequently, the family is suing the facilitators, the group home where the young man lived, and the Crown. While being kept from his son, the father did some of his own research, only to discover that over 17

lawsuits are being launched in North America due to similar allegations ("Parents Falsely Accused," 1994).

Although it is understood that child welfare professionals cannot turn a blind eye to abuse allegations made during the process of facilitated communication, more care is needed when deciding what to do with this information. What needs to be accepted is that any child is highly vulnerable to manipulation when it comes to abuse allegations and a child with autism is no exception. This becomes a real issue with facilitated communication, as a vehicle for manipulation appears to be built right into it (Richler, 1994).

It has been recommended that before any investigation is launched regarding an abuse allegation, there first must be a process of validating independent communication. This process must be kept totally separate from any type of abuse investigation. Without this, any investigation is highly flawed and can have devastating results (Heckler, 1994; Howlin, 1994; Jones, 1994; Richler, 1994; Starr, 1994). What has been discovered is that in a vast majority of these cases, the child has been unable to prove independent communication (Jones, 1994). Like with all well-balanced investigations, corroborating evidence, such as sexualized play or medical evidence, must also be considered.

In one case, validation of independent communication was not substantiated through an empirical, yet simple study. The researcher was very careful not to complicate the study, or depersonalize it in order to convey the respect support Biklen and associates claim is essential (Heckler, 1994). Heckler was able to

generate some statements which were true and totally unknown to the facilitator. As a result he contended that although empirically independent communication could not be proven, there was some evidence of validity. It is also important to note that the child's communications led to information regarding parents' inappropriate language around their child, as well as the viewing of pornographic movies in the presence of their child (Heckler, 1994).

Until facilitated communication is empirically validated, situations such as these will continue to occur. The impact these lawsuits will have on agencies who continue to support facilitated communication is not known. Allegations of abuse made by children through facilitated communication puts parents in a very vulnerable position, especially if prior to these allegations parents were high supporters of the technique. It is likely facilitated communication may never be globally validated, but will need to be on an individual basis.

POLICY AND SOCIAL WORK IMPLICATIONS

Need for Early and Community Intervention Techniques

Proponents of facilitated communication hope that in light of this technique, there will be more focus on augmentative and alternative communicational assessments and interventions with preschoolers who are showing delays in speech acquisition, regardless of any other impairments they have been diagnosed to have. The screening of fine motor skills should be part of this early assessment phase. If children are assessed at having adequate hand skills they can be given access to other

forms of augmentative communication, and will not require facilitated communication (Crossley, 1992).

There needs to be a re-evaluation of people with severe communication impairment (SCI). Many of these people have been assessed as intellectually impaired because they have not been able to "prove" their intelligence with the examination tools they have been provided with. There must be a means to measure intelligence which is not influenced by expressive impairments. Detailed neuromotor assessments on infants with severe speech delays and early speech and physical intervention could improve things significantly (Crossley, 1992).

Perhaps most importantly, there needs to be a move to extend children's communication abilities outside of the treatment program and into the community. This includes allowing children to learn how to shop, bank, and even travel by using portable communication aids. The community at large needs to be open to the potentials of SCI individuals, and to provide an arena for these people to communicate (Crossley, 1992). Calculator (1992a) recommends a more indepth look at the changes in people's lives, focusing on quality of life indices following training in facilitated communication (Calculator, 1992a). There is a real need to be aware and sensitive to the rights of people with SCI (Crossley, 1992).

Donnellan et al. comment on sceptics' contention that exposing children and their families to an empirically invalid procedure is unethical and dangerous. The authors believe that **not** offering the opportunity for these children and families to try facilitated communication is far more dangerous than raising the hopes of these

families. This is only so long as the child with autism is not blamed for not being able to communicate. Families have survived many other disappointments far more costly. Families need to be encouraged to try a myriad of augmentative communication techniques. Again, facilitated communication is only one of many communication techniques which borrows from an eclectic source of research data and practice skills. Gaining clearer understanding of these sources and their inter-relatedness will hopefully lead to a better understanding of how they operate in facilitated communication (Donnellan et al., 1992).

EDUCATION POLICY IMPLICATIONS

The role of facilitated communication in the education system has led to some practical considerations about schooling and the integration of children using the technique. The first is that education professionals are going to need to find a way to integrate these children and allow them to participate in academic exercises via facilitated communication. In order for this to occur, some children's individualized programs may have to be altered for primarily functional, community-based curricula to a combination of functional and academic curricula (Biklen & Schubert, 1991).

A second consideration is the fact that these students will require facilitators in order to participate in classes. Classmates, if trained properly, could conceivably fulfil this role. Third, facilitators must work to fade support in order for students to gain a greater level of independence. A fourth consideration is that schools will have to look into acquiring the equipment needed for facilitated communication, such as inexpensive electronic typewriters or portable computers, desktop computers or small

typing devices such as a Canon Communicator. These types of devices are more desirable than alphabet boards because they are able to keep records of students' work. The Canon Communicator, because it is small and portable, is probably the most feasible (Biklen & Schubert, 1991).

Fifth, teachers will need to make arrangements to train parents to facilitate in order to foster an environment at home which is conducive to the student doing homework. It also will allow students to extend their communicational abilities into the home and community. A sixth consideration comes out of what has been the norm in the introduction of children with autism to facilitated communication. A special education teacher or speech pathologist has probably been the one to introduce the technique, and often these people need to work as consultants with the school system in order to allow for the full integration of students using facilitated communication (Biklen & Schubert, 1991). At the agency from which this researcher's data was derived, the speech therapist working there has been putting in many hours working with schools and parents in order to train people to be facilitators.

A final consideration is that many of these students, with the aid of facilitation, have been able to reveal not only academic ability, but also humour, creativity, and intellectual interest that has never been seen prior to the introduction of facilitated communication (Biklen & Schubert, 1991).

A very important precaution which must be taken when moving towards integration for children using facilitated communication is making sure the

equipment and staff are available. The term "maindumping" has been used to describe the phenomenon of mainstreaming disabled students without the support of essential resources and equipment needed. In this way the student does not benefit from placement (Remington-Gurney & Crossley, 1990). As far as progress goes for children who are using facilitated communication, this is only possible if given the opportunity to access communication devices.

RESEARCHER'S REMARKS

When I first began to visualize this study in the fall of 1991, there was essentially no literature yet available on facilitated communication. Yet, in the past two and a half years, the field of autism has been overrun by the subject of facilitated communication. Periodicals, once devoid of any such mention of facilitated communication, are devoting entire issues to the subject. Agencies geared towards helping people with communication deficits have embraced this technique, and have clashed with other agencies and professionals over it. Autism, basically, not considered newsworthy, has received more media coverage in the past few years than it has in the last forty years. If anything, one can say that facilitated communication has helped in boosting awareness and empathy for people with autism.

What struck me while conducting this study was the complete devotion both parents and professionals had for the children in my study. They were excited about what facilitated communication could mean for these children, yet at the same time, showed a seasoned wariness about becoming too optimistic. Agency staff, although at first very protective of their clients, were very helpful and supportive of my study.

They were eager to share their experiences, doubts, and hopefulness regarding this population. It would be interesting to see how these children are doing now, as when I studied them, they were all just starting.

Proponents of facilitated communication agree that the fact that the technique requires the support of another person in order for the communicator to "speak" is a problem. They agree that there is a risk of facilitators inadvertently influencing the communicator. They also agree the whole dependency factor is an issue. Facilitated communication is not the ideal form of augmentative communication, but is the only solution for some clients who have neuromotor impairments (Crossley, 1992).

In summary, it must be noted that due to culminating contrary evidence, some agencies who were once very pro-facilitated communication are now revoking their support and advocacy. One such agency is Surrey Place in Toronto. Some schools are no longer supporting facilitated communication. Whether or not this is a trend is not known. The Geneva Centre continues to support facilitated communication and has focused much of its literature on ways to avoid influencing the communicator. There also continues to be a number of people with first hand experience who report that children have communicated personal things they (the facilitators) would have no way of knowing. At this time the future of facilitated communication is very questionable, as its survival will depend of funding and agency support.

SUMMARY

This chapter discussed the results of this study, and whether these results are consistent with the literature. Possible explanations were also provided regarding

certain responses, highlighting those areas that would benefit from future research. Future implications in policy, theory, and social work practice were discussed.

Purpose of the Study

The purpose of this study is to investigate the experiences of parents and professionals with the technique of facilitated communication. Facilitated communication has been receiving a great deal of attention in the past couple of years, specifically in the area of autism. Autism has been subject to much controversy since it was first identified by Leo Kanner in 1943 regarding the etiology of the disorder and its subsequent treatment.

Facilitated communication has become a controversy as it calls into question theories surrounding autism and its causes. Because both areas of study (autism and facilitated communication) are areas where differing views and belief systems prevail, this researcher thought it would be interesting to study how parents, children, and professionals are experiencing facilitated communication. From this study, further research questions and/or hypothesis could be generated for further study.

The Research Question

This study attempts to answer the question: What are the experiences of parents, children, and professionals with the technique of facilitated communication?

Operationalization of Variables

Experiences in this study include family demographics, children's behaviours, children's IQ/functioning level, age at diagnosis, school, children's communication

characteristics, involvement/interest in facilitated communication, and emotional response to children's success at facilitated communication.

Facilitated communication is operationalized as a technique whereby an individual communicates with the physical and emotional support of another individual known as a facilitator, by pointing to objects, pictures or letters.

Autism is operationalized through the diagnosis given by a physician. The children in this study were diagnosed as autistic by DSM-III-R criteria.

Children include the natural, step, or adopted offspring of parents involved in the parent support group operating through the Society for the Treatment of Autism, who may or may not be using facilitated communication. These children are referred to as "clients" by the professionals in the sample and are involved in the Society for the Treatment of Autism who may or may not be involved in facilitated communication.

Professionals include social workers, teachers, child care workers, speech pathologists, psychologists, and psychiatrists. All professionals in this study have some knowledge of facilitated communication and are connected with the Society for the Treatment of Autism.

Methodology

Two separate questionnaires were used in this study: the parent questionnaire (Appendix B) and the professional questionnaire (Appendix D). Each questionnaire was accompanied by an informed consent form (Appendices A and C). Data from these populations was collected on two separate occasions.

Parents were given the questionnaires at a parent support group meeting on September 15, 1992. Nine questionnaires were completed. Additional questionnaires were mailed out by the group president to those members who did not make the meeting that night. Two questionnaires were returned.

Twenty-five questionnaires were handed out to staff mailboxes at the Society on September 17, 1992. Three weeks was the time frame allotted to have these questionnaires completed. Sixteen questionnaires were returned.

The questionnaires were developed through consultation with Rimland's E-2 (Rimland, 1980), the literature, and experts. Face validity was established through consultation with two experts in the field of autism.

The research design used in this study is an ex-post-facto design, which does not control for any internal validity threats. Because the questionnaires used in this study were designed specifically for this study, except for face validity, they hold no validity or reliability. The parent questionnaire relies a lot on parents' memory, and this could also be a source of error. Two parents did not fill out the questionnaire at the parent support group, and therefore did not have the opportunity to ask questions as the other nine did. It is not known under what conditions these two parents and the sixteen professionals completed the questionnaire.

This study targeted two specific groups of people and results are not intended to be generalized to other populations. Relatively small sample sizes also makes it difficult to generalize to all workers at the Agency.

Since the Agency in question is very pro-facilitated communication, the sample may be biased.

The Role of Theory

Family systems theory suggests that "treating" and educating the entire family is essential for families with handicapped members (Kostantareas, 1990; Harris, 1984; Bristol, 1985; Salomon, 1981). Families with autistic members may be experiencing a great deal of stress, and unless this stress can be reduced, families may feel too overwhelmed to care for their autistic child. A major focus of the family systems approach is deciphering those areas which are most stressful and coming up with strategies to relieve this stress (Kostantareas, 1990; Harris, 1984; Bristol, 1985; Salomon, 1981).

It is believed that improvement in one area will ultimately be experienced in other areas. The family systems approach seeks to instill in parents a sense of competency and empowerment. As stresses become more manageable, parents are then able to become more focused in areas which require a lot of their attention (Harris, 1984). The sooner families become involved with this type of intervention the more likely these families will be able to cope (Prizant et al., 1988; Kostanareas, 1990).

Children diagnosed as autistic often have great difficulty communicating, and this is very stressful for parents (Prizant & Wetherby, 1988; DeMyer, 1979; Wing, 1980; Lapin & Lapin, 1976; Donovan, 1988; Marcus, 1977). Facilitated communication addresses this area specifically, which some parents may find very appealing.

However, the rate of acquisition of this technique by children varies considerably. Also, not all parents who attempt facilitation become anywhere near as successful as the professionals working with these children (Biklen, 1992; Prior & Cummins, 1992). Indeed, the parents in my sample who had been attempting facilitated communication with their children were only having limited success, where professionals in the sample were experiencing a much higher level of success. However, this could be due to differing lengths of time working at facilitating. Critics of facilitated communication argue that many parents are led to believe that facilitated communication is the magic answer to their children's problems (Prior & Cummins, 1992; Schopler, 1992).

In this light, it is questionable if facilitated communication heightens parental stress or lowers it. Parents in the sample did respond positively to the idea of facilitated communication, but were reserved in their prognosis of their own children. However, in the spirit of systems theory, the importance of involving family in the technique of facilitated communication cannot be understated.

Moroz (1989) writes of the importance of involving the family with the education system. Facilitated communication and integration have come to be a major forces in the area of autism. Integration of the handicapped is seen as a progressive approach to the management and education of this population (Remington-Gurney & Crossley, 1990; Biklen, 1990; Biklen & Schubert, 1991; Biklen et al., 1991). It is believed that the use of facilitated communication in the classroom will lead to a greater level of integration of children with autism. Given the

opportunity to use facilitated communication may allow students a greater opportunity to socialize with others, and work up to their academic potential (Remington-Gurney & Crossley, 1990). Parents who learn to facilitate with their children may be able to help with homework, and allow children to talk about their school experiences.

An important part of systems theory is hooking families up with other families who share similar experiences. This may relieve feelings of isolation, and allow parents to share information and work together to advocate for their children (Prizant et al., 1988; Wintersteen, 1988). Involving parents in treatment and school may help facilitate this (Moroz, 1988). The parents in this study are all part of a parent support group run through the Society for the Treatment of Autism. Integration and the use of facilitated communication in the classroom was still at the early stages in the sample; so the outcomes were not available at the time of the study. A study conducted by Remington-Gurney and Crossley (1990) in Melbourne regarding integration and autism was quite positive.

SUMMARY OF KEY FINDINGS

Parents and Children

Most children had been exposed to a number of augmentative communication techniques prior to facilitated communication; however, these had been met with a limited amount of success. Only one child was able to use sentences, and three were not able to communicate with these techniques.

Only three of the children were in integrated schools, while six were in segregated classrooms. The majority of parents believe that facilitated communication increases the likelihood of integration, however, only one parent reported his/her child was using facilitated communication in the classroom.

Five parents reported that their children had been exposed to facilitated communication, successful to varying degrees. Two were able to use sentences and single words and three pointed correctly to pictures and symbols. Only four parents had been successful facilitators; however, none of the children were able to communicate in sentences. One parent did not want his/her child involved with facilitated communication. Seventy percent of parents wanted to be involved in facilitated communication, while another thirty percent were not sure.

The majority of parents were somewhat or very confident in the authenticity of facilitated communication. Only one parent was decidedly sceptical. When asked about sources of support, eight of the eleven parents mentioned the parent support group. Incidentally this was mentioned more often than spouses or family. Seven parents agreed that facilitated communication challenges theories which view autism as a social-cognitive-language disorder. Over half of the parents also questioned the view that autism limits a person's ability to understand the world around him. Parents were less clear when questioning past assessments given to their children prior to facilitated communication. Again, this may have much to do with what the assessments were and if parents believed them in the first place.

Parents have not really changed the way they relate to their children in light of facilitated communication. Two parents have consciously found themselves relating to their children on a higher level. Facilitated communication has not changed the amount that parents worry about their children's future. It is important to note that with this sample of parents, facilitated communication is still a relatively new concept and its full effects may not have been fully realized at the time this study was done. It may be some time before we know exactly what the impact of facilitated communication has on children and their families.

The Professionals

Nine of the professionals were somewhat or very confident in the authenticity of facilitated communication, and half felt that support for the technique was high at the workplace.

Twelve professionals had been successful as facilitators to varying degrees. Five reported to have worked with children who have produced sentences. Fifteen had had the opportunity to at least observe a child doing facilitated communication. Eleven professionals found themselves questioning theories that view autism as a social-cognitive-language disorder since the introduction of facilitated communication. An overwhelming majority (fifteen) found themselves questioning the idea that children with autism are unable to understand the world around them. Ten found themselves questioning children's past assessments.

Unlike parents, many professionals (ten) began relating to their clients on a higher level after the introduction of facilitated communication. Ten professionals

also felt their clients had a chance to achieve a higher level of independence than previously. Nine saw facilitated communication as leading to a higher incidence of integration. Fourteen professionals had clients in mind who they felt would benefit from using facilitated communication in the classroom.

Facilitated communication remains a sort of enigma to many people. Theories run rampant, but there is still no explanation as to why it works that everyone is comfortable with. Many professionals choose not to look at the why and how of the technique. Their argument is if it works and the child appears to benefit from it, then what is the harm. Others believe there is a moral and ethical obligation to exhaust all possibilities and tests in order to achieve a level of validity. Many professionals would argue that this has not been established and for this reason, facilitated communication has no business in the treatment, management, or education of the autistic population.

Certainly more research in this area is warranted, not only to verify its authenticity, but on family dynamics. It has been my experience that dissention in the home surrounding facilitated communication can lead to much family dysfunction. Perhaps in the next ten years, outcome studies can be done on those students and their families who have been our pioneers of facilitated communication.

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APPENDIX A

INFORMED CONSENT FORM

September 1992

Dear Parent:

My name is Colleen Trapp and I am a graduate student, working on my Master's degree in Social Work. Since hearing about the technique of Facilitated Communication I have become increasingly interested in how the autism community has responded to this innovative method. Facilitated Communication has stirred up a great deal of controversy because it challenges those steadfast beliefs that children with autism are unable to understand or relate to the world around them. Autistic children have often been assessed as mentally challenged and low functioning. On the contrary, many children who have been able to communicate through Facilitated Communication have demonstrated high literacy skills, intelligence, and conviction.

You, as caregivers, hold an important role in these children's lives, and your opinions are of equal importance. As part of the autism community, your thoughts regarding Facilitated Communication and what it means to you and your child is an area which is worth exploring as Facilitated Communication gains more acceptance.

The attached questionnaire is for a study I am conducting in order to explore the experiences of parents with the technique of Facilitated Communication. A number of different areas are covered within this questionnaire. These areas include family demographics, your child's behaviours, your child's assessed functioning level, your child's communication history, your child's educational experience, and any concerns you as a parent may be experiencing. This information will allow this researcher to get a clearer idea of what types of situations families are experiencing, and may shed light on possible areas where social and educational services may be beneficial.

PROCEDURES AND SAFEGUARDS

Participation in this study is completely voluntary, and you are free to withdraw from the study at any point in time. There are no right or wrong answers to questions, and you are not obliged to answer questions you do not wish to. If you require clarification on a question please feel free to ask.

The questionnaire will require approximately one half hour of your time, and only needs to be completed once. Completed questionnaires will be kept confidential, and will only be viewed by this researcher. Information provided will be used to compile aggregated data, and will not reflect individual characteristics.

Questionnaires will be held in this researcher's possession until coded, and then will be destroyed. Although each questionnaire is numbered, this is for data processing only, and numbers cannot be used to trace individual respondents. Anonymity is assured.

PARTICIPANT'S CONSENT

Your cooperation is very much appreciated. If you desire access to the results of this study please indicate by checking the appropriate box below:

I would like a summary of the results of this study.

I do not require a summary of the results of this study.

Your signature below on this 'consent form' indicates that you have understood to your satisfaction the information regarding your participation in the research project. In no way does this waive your legal rights nor release the researcher from legal and professional responsibilities. If you have any questions concerning your participation in this study please feel free to contact me at 265-5694.

Participant's Signature

Date _____

APPENDIX B
PARENT QUESTIONNAIRE

I This section is intended to provide an understanding of your child and your family.

1.1 What is your relationship to your child?
(Circle one number below)

1. Mother (includes step)
2. Father (includes step)
3. Legal guardian
4. Other_____ (please specify)

1.2 What is your age? (Circle one number below)

1. Under 20 years
2. 20-29 years
3. 30-39 years
4. 40-49 years
5. 50-59 years
6. More than 60 years

1.3 What age is your child? (Write age in years in blank provided)
____years

1.4 What is your child's gender? (Circle one number below)

1. Male
2. Female

1.5 Please fill in the blanks below with the appropriate number:

Child is the ____ born of ____ children.

1.6 Is your child a twin? (Circle one number below)

1. Yes, an identical twin
2. Yes, a non-identical twin
3. No

1.7 Please check () if any of the difficulties below applies to any members of your extended family. If that family member is a sibling of your child, check twice () and check three times () if the sibling is a twin.

1. Autism____
2. Mentally challenged____
3. Learning disabled____
4. Aphasia____
5. Pervasive developmental disorder not otherwise specified____
6. Fragile X syndrome____
7. Other_____ (please specify)
8. Don't know

1.8 At what age did you suspect your child was experiencing some difficulty (or was different)? (Circle one number below)

1. In first 3 months
2. 4-6 months
3. 7-12 months
4. 13-24 months
5. 2-3 years
6. 3-4 years
7. After 4 years
8. Don't know

1.9 At what age was your child diagnosed with autism?
(Circle one number below)

1. In first 3 months
2. 4-6 months
3. 7-12 months
4. 13-24 months
5. 2-3 years
6. 3-4 years
7. After 4 years
8. Don't know

1.10 At what level was your child assessed to be functioning at according to the most recent assessment (Circle one number below)

1. Well under chronological age level
2. Somewhat under chronological age level
3. Slightly under chronological age level
4. At chronological age level
5. Slightly above chronological age level
6. Somewhat above chronological age level
7. Well above chronological age level
8. Don't know

1.11 Where is your child living at this time? (Circle one number below)

1. With you and your spouse
2. With your ex-spouse
3. With relatives
4. In foster home
5. In group home
6. In treatment centre
7. In hospital
8. Semi-independent living
9. Independent living
10. Other_____ (please specify)

II This section pertains to your child's behaviours.

2.1 Please circle the most appropriate number to describe the frequency your child engages in the behaviours listed below.

	Never				Always
E.g., Tantrum	1	2	3	4	5
	Never				Always
Tantrums	1	2	3	4	5
Aggression	1	2	3	4	5
Self-abusive	1	2	3	4	5

	Never				Always
Stereotypical behaviours (i.e., rocking, arm-flapping)	1	2	3	4	5
Destroys objects/clothing	1	2	3	4	5
Chants/sings	1	2	3	4	5
Fixations with objects/ activities/people	1	2	3	4	5
Appears oblivious of environment	1	2	3	4	5
Appears overly sensitive	1	2	3	4	5
Odd/impaired mobility	1	2	3	4	5
Repetitive play	1	2	3	4	5
Exhibits need for sameness	1	2	3	4	5
Lines objects up	1	2	3	4	5
Little or no eye contact with others	1	2	3	4	5
Does not initiate contact with others	1	2	3	4	5
Toiletting problems	1	2	3	4	5
Masturbates	1	2	3	4	5
Ritualistic behaviours	1	2	3	4	5
Appears "hyperactive"	1	2	3	4	5
Appears lethargic	1	2	3	4	5
Mouths/eats inedible objects	1	2	3	4	5
Appears to laugh out of context	1	2	3	4	5
Other _____ (please specify)	1	2	3	4	5

2.2 Does your child show an unusual degree of skill, much better than other children his age, at any of the following? (Circle as many numbers as apply)

1. Assembling jigsaw or similar puzzles
2. Arithmetic computation
3. Can tell day of week a certain date will fall on
4. Perfect musical pitch
5. Throwing and/or catching a ball
6. No unusual skill, or not sure
7. Other _____ (please specify)

2.3 Is your child extremely fearful? (Circle one number below)

1. Yes, of strangers or certain people
2. Yes, of certain animals, noises or objects
3. Yes, of 1 & 2
4. Only normal fearfulness
5. Seems unusually bold and free of fear
6. Child ignores or is unaware of fearsome objects

2.4 How well physically coordinated is your child at running, walking, balancing, climbing? (Circle one number below)

1. Unusually graceful
2. About average
3. Somewhat below average, or poor

2.5 Does your child hold his body or parts of his body in strange postures? (Circle one number below)

1. Yes, sometimes or often
2. No

2.6 How skilful is your child in doing fine work with his/her fingers or playing with small objects? (Circle one number below)

1. Exceptionally skilful
2. Average for age
3. A little awkward, or very awkward
4. Don't know

III This section pertains to your child's communication abilities PRIOR to your child attempting Facilitated Communication.

3.1 What level of understanding did your child appear to have of spoken word? (Circle one number below)

1. High level
2. Medium level
3. Low level
4. None
5. Don't know

3.2 At what age did your child begin to talk (even if s/he later stopped talking)? (Circle one number below)

1. Has never used words
2. 8-12 months
3. 13-15 months
4. 16-24 months
5. 2-3 years
6. 3-4 years
7. After 4 years
8. Don't know

3.3 Did your child progress in his/her speech ability? (Circle one number below)

1. Yes, a lot
2. Yes, a little
3. No
4. Not sure

3.4 Did your child stop speaking after acquiring speech? (Circle one number below)

1. Never has used speech
2. Yes, but started to talk again after a period of silence
3. Yes, and has never spoken again
4. Never stopped speaking
5. Not sure

- 3.5 What type of verbal communication does your child typically exhibit?
(Circle one number below)
1. No verbal communication
 2. Single words or word approximations
 3. 2-word phrases
 4. Echoed words/sentences, either delayed or immediate
 5. Combination of echoed words/sentences and original words/sentences
 6. All original sentences
- 3.6 Does your child use pronouns (I and You) accurately? (Circle one number below)
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never
 6. No verbal communication
- 3.7 What type(s) of communication techniques have been attempted with your child? (Circle as many numbers as apply)
1. Bliss symbols
 2. Sign language
 3. Picture boards
 4. Total communication (speech and sign)
 5. Gestural
 6. Speech therapy
 7. Other_____ (please specify)
- 3.8 Did you find these techniques to be successful? (Circle one number below)
1. Yes, was able to use sentences
 2. Yes, was able to use small phrases
 3. Yes, was able to use words
 4. Yes, was able to communicate wants and needs through symbols and gestures
 5. No, was not able to communicate
 6. My child was not exposed to other communication techniques

IV This section pertains to your child's school experience.

4.1 Is your child in a classroom with non-handicapped students (integrated classroom)? (Circle one number below)

1. Yes, with students older than my child (full or part-time)
2. Yes, with students the same age as my child (full or part-time)
3. Yes, with students younger than my child (full or part-time)
4. No, child in special education class full-time
5. My child is not placed in school at this time
6. My child is too young for school

4.2 Do you want your child in an integrated classroom? (Circle one number below)

1. Yes
2. No
3. Not sure

4.3 Respond to the statement below:

Facilitated Communication makes integration of autistic children in mainstream schools more possible. (Circle one number below)

very much
disagree

very much
agree

1

2

3

4

5

4.4 Have you or someone else working with your child suggested to your child's school the possibility of using Facilitated Communication in the classroom? (Circle one number below)

1. Yes
2. No
3. Don't know

4.5 What kind of response did the school give to this suggestion? (Circle one number below)

1. Quite positive
2. Somewhat positive
3. Neutral
4. Somewhat negative
5. Quite negative
6. Have not approached school
7. Don't know

4.6 Has your child been using Facilitated Communication in the classroom? (Circle one number below)

1. Yes
2. No, but I would like him/her to
3. No
4. Don't know

4.7 What was the outcome of your child using Facilitated Communication in the classroom? (Circle one number below)

1. Very positive
2. Positive
3. Neither positive or negative
4. Negative
5. Very negative
6. Does not apply to my child

V This section pertains to Facilitated Communication and you and your child.

5.1 How did you first hear about Facilitated Communication? (Circle one number below)

1. Media
2. Friends
3. Treatment Centre
4. School
5. Autism Newsletters
6. Journals and articles
7. Other_____ (please specify)

5.2 Has your child been involved with Facilitated Communication? (Circle one number below)

1. Yes
2. No
3. Not sure

5.3 Has your child been able to communicate through Facilitated Communication? (Circle one number below)

1. My child has not used Facilitated Communication
2. Yes, in sentences
3. Yes, in two to three word phrases
4. Yes, in single words
5. Yes, points to pictures and/or symbols
6. No
7. Not sure

5.4 Do you want your child to be involved in Facilitated Communication? (Circle one number below)

1. Yes
2. No
3. Not sure

5.5 Have you tried facilitating with your child? (Circle one number below)

1. Yes
2. No

5.6 Have you been able to successfully facilitate with your child on at least one occasion? (Circle one number below)

1. Yes, child used sentences
2. Yes, child used two to three word phrases
3. Yes, child used single words
4. Yes, child pointed to pictures and/or symbols
5. No

5.7 Do you want to facilitate with your child? (Circle one number below)

1. Yes
2. No
3. Not sure

5.8 Have you been able to observe your child communicating through Facilitated Communication? (Circle one number below)

1. Yes
2. No

5.9 What best describes your position regarding the authenticity of Facilitated Communication? (Circle one number below)

1. Very sceptical
2. Somewhat sceptical
3. Neutral
4. Somewhat confident
5. Very confident

5.10 What needs to happen in order for you to be confident (or more so) in the authenticity of Facilitated Communication? (Circle one number below)

1. More research needs to be done
2. My child needs to do it with more facilitators
3. I need to see my child do it
4. My child needs to do it
5. I need to do it with my child
6. I need to see more children do it
7. I'm confident of the authenticity of Facilitated Communication
8. Other_____ (please specify)

5.11 On the scale below indicate the level of support you perceive to exist for you in your position regarding Facilitated Communication. (Circle one number below)

high
level

low
level

1

2

3

4

5

5.12 Where does this support come from? (Circle as many numbers below that apply)

1. Spouse
2. Children
3. Extended family
4. Professionals
5. Community/parent support group
6. Friends
7. School
8. Other_____ (please specify)

5.13 Please indicate whether you agree or disagree with the following statements.

1. Facilitated Communication challenges those theories that say autism is a social-cognitive-language disorder. (Circle one number below)

very much
disagree

very much
agree

1 2 3 4 5

2. Facilitated Communication challenges the view that autism limits children's abilities to relate to and understand the world around them. (Circle one number below)

very much
disagree

very much
agree

1 2 3 4 5

3. I now find myself questioning past assessments my child has been given. (Circle one number below)

very much
disagree

very much
agree

1 2 3 4 5

- 5.14 In light of Facilitated Communication, at what level are you relating to your child? (Circle one number below)
1. Higher than previously
 2. About the same
 3. Lower than previously
 4. Not sure
- 5.15 Prior to the introduction of Facilitated Communication did you worry about your child's future? (Circle one number below)
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never
- 5.16 Since the introduction of Facilitated Communication, has the amount of worry you experience about your child's future changed? (Circle one number below)
1. Yes, I worry less
 2. Yes, I worry more
 3. No, I worry about the same
 4. Not sure
- 5.17 Have you seen a change in your child's behaviours since being introduced to Facilitated Communication? (Circle one number below)
1. Yes
 2. No
 3. Not sure
 4. My child has not been introduced to Facilitated Communication
- 5.18 Please describe changes in your child's behaviours.

- 5.19 Describe your reaction to the possibilities of Facilitated Communication and your child.

- 6.0 This section pertains to any areas of concern you may or may not have.

- 6.1 Please circle the most appropriate number to describe the level of concern you experience with each of the areas listed below in regard to your child.

	high level				low level
Behaviours	1	2	3	4	5
Communication	1	2	3	4	5
Social skills	1	2	3	4	5
Safety	1	2	3	4	5
Finances	1	2	3	4	5
Health Issues	1	2	3	4	5
Residence	1	2	3	4	5
Other_____					
(please specify)	1	2	3	4	5

APPENDIX C
INFORMED CONSENT FORM

September, 1992

Dear Professional:

My name is Colleen Trapp and I am a graduate student, working on my Master's degree in Social Work. Since hearing about the technique of Facilitated Communication I have become increasingly interested in how the autism community has responded to this innovative method. Facilitated Communication has stirred up a great deal of controversy because it challenges those steadfast beliefs that children with autism are unable to understand or relate to the world around them. Autistic children have often been assessed as mentally challenged and low functioning. On the contrary, many children who have been able to communicate through Facilitated Communication have demonstrated high literacy skills, intelligence, and conviction.

As professionals you hold an important role in these children's lives, and your opinions are important. As part of the autism community, your thoughts regarding Facilitated Communication and what it means to you and your clients is an area which is worth exploring as Facilitated Communication gains more acceptance. The attached questionnaire is for a study I am conducting in order to explore the experiences of professionals with the technique of Facilitated Communication. Therefore your experience as a professional in the area of autism can be a contribution to this study.

PROCEDURES AND SAFEGUARDS

Participation in this study is completely voluntary, and you are free to withdraw from the study at any point in time. There are no right or wrong answers to questions, and you are not obliged to answer questions you do not wish to. Participation in this study has no bearing on your role as a professional. If you require clarification on a question please feel free to contact this researcher through the number listed below.

The questionnaire will require approximately fifteen minutes of your time, and only needs to be completed once. Completed questionnaires will be kept confidential, and will only be viewed by this researcher. Information provided will be used to compile aggregated data, and will not reflect individual characteristics. Questionnaires will be held in this researcher's possession until coded, and then will be destroyed. Although each questionnaire is numbered, this is for data processing only, and numbers cannot be used to trace individual respondents. Anonymity is assured.

Please place the completed questionnaire in the envelope provided and put the sealed envelope in the box provided by this researcher at reception. All questionnaires will be picked up by this researcher on September 28, 1992.

PARTICIPANT'S CONSENT

Your cooperation is very much appreciated. If you desire access to the results of this study please indicate by checking the appropriate box below:

I would like a summary of the results of this study.

I do not require a summary of the results of this study.

Your signature below on this 'consent form' indicates that you have understood to your satisfaction the information regarding your participation in the research project. In no way does this waive your legal rights nor release the researcher from legal and professional responsibilities. If you have any questions concerning your participation in this study please feel free to contact me at 265-5694.

Participant's Signature

Date _____

APPENDIX D
PROFESSIONAL QUESTIONNAIRE

I. This section is intended to provide an understanding of you and your work with autistic children.

1.1 In what capacity are you presently involved with autistic children? (Circle one number below)

1. Teacher
2. Social worker
3. Child care worker
4. Speech therapist
5. Psychologist
6. Psychiatrist
7. Other_____ (please specify)

1.2 How long have you worked with autistic children in a professional capacity? (Circle one number below)

1. Less than 1 year
2. 1-5 years
3. 6-10 years
4. 11-15 years
5. 16-20 years
6. More than 20 years

1.3 How long have you been employed in your present position? (Circle one number below)

1. Less than 1 year
2. 1-5 years
3. 6-10 years
4. 11-15 years
5. 16-20 years
6. More than 20 years

- 1.4 What age are you? (Circle one number below)
1. Less than 20 years
 2. 20-29 years
 3. 30-39 years
 4. 40-49 years
 5. 50-59 years
 6. More than 60 years
- 1.5 What is your gender? (Circle one number below)
1. Male
 2. Female
- 2.0 **This section pertains to Facilitated Communication and you and your clients.**
- 2.1 How did you first hear about Facilitated Communication? (Circle one number below)
1. Media
 2. Parents of your clients
 3. Colleagues
 4. Workplace
 5. Autism newsletters
 6. Journals and articles
 7. Other_____ (please specify)
- 2.2 What best describes your position regarding the authenticity of Facilitated Communication? (Circle one number below)
1. Very sceptical
 2. Somewhat sceptical
 3. Neutral
 4. Somewhat confident
 5. Very confident

2.3 What needs to happen in order for you to be confident (or more so) in the authenticity of Facilitated Communication? (Circle one number below)

1. More research needs to be done
2. I need to facilitate with a child
3. I need to observe a child communicate through Facilitated Communication
4. I need to see a child communicate with different facilitators
5. I need to see more children do it
6. I'm confident of the authenticity of Facilitated Communication
7. Other_____ (please specify)

2.4 On the scale below indicate the level of support you perceive to exist in your agency for Facilitated Communication (Circle one number below)

high level		none at all		
1	2	3	4	5

2.5 Have you acted as a facilitator for a child and been successful on at least one occasion? (Circle one number below)

1. Yes, child used sentences
2. Yes, child used two to three word phrases
3. Yes, child used single words
4. Yes, child pointed to pictures and/or symbols
5. No

2.6 Do you want to learn to be a facilitator? (Circle one number below)

1. I've already learned
2. Yes, I'd like to learn
3. No, I would not
4. I'm not sure

2.7 Have you observed, other than on television, a child communicate through Facilitated Communication? (Circle one number below)

1. Yes
2. No

2.8 Please indicate whether you agree or disagree with the following statements:

1. Facilitated Communication challenges those theories that say autism is a social-cognitive-language disorder. (Circle one number below)

very much disagree			very much agree	
1	2	3	4	5

2. Facilitated Communication challenges the view that autistic children are severely handicapped in their ability to understand the world around them. (Circle one number below)

very much disagree			very much agree	
1	2	3	4	5

3. I now find myself questioning past assessments my clients have been given. (Circle one number below)

very much disagree			very much agree	
1	2	3	4	5

2.9 In light of Facilitated Communication, at what level are you relating to your clients? (Circle one number below)

1. Higher than previously
2. About the same
3. Lower than previously
4. Not sure

- 2.10 Since the introduction of Facilitated Communication do you think your clients have a chance to achieve a higher level of independence than you thought previously? (Circle one number below)

1. Yes
3. No
4. Not sure

III. This section pertains to your client's education.

- 3.1 Please indicate whether you agree or disagree with the statement below.

Facilitated Communication makes integration of autistic children in mainstream schools more possible. (Circle one number below)

very much disagree			very much agree	
1	2	3	4	5

- 3.2 Have you or a colleague suggested to schools the possibility of Facilitated Communication in the classroom? (Circle one number below)

1. Yes
2. No
3. Don't know

- 3.3 What kind of response did the school give to this suggestion? (Circle one number below)

1. Quite positive
2. Somewhat positive
3. Neutral
4. Somewhat negative
5. Quite negative
6. Haven't approached school
7. Don't know

- 3.4 Can you think of clients right now who you think would benefit from Facilitated Communication in the classroom? (Circle one number below)
1. Yes
 2. No
 3. Not sure
- 3.5 Have any of your clients been using Facilitated Communication in the classroom? (Circle one number below)
1. Yes
 2. No
 3. Don't know
- 3.6 How many of your clients are using Facilitated Communication in the classroom? (Fill in blank provided below)
- _____
- 3.7 How many of your clients do you think should be using Facilitated Communication in the classroom? (Fill in blank provided below)
- _____
- 3.8 Prior to Facilitated Communication, generally how often did you think your clients were understanding what was spoken to them? (Circle one number below)
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never
- 3.9 Describe your thoughts regarding the possibilities of Facilitated Communication and autistic people.

APPENDIX E**PROFESSIONAL REMINDER LETTER**

Dear Professional:

February, 1992

A few weeks ago a questionnaire was delivered to you requesting information about you and the technique of Facilitated Communication. If you have not already completed this questionnaire I would again request that you do so, as through this study I expect to acquire very useful information in the area of Facilitated Communication and those people working professionally with autistic children.

Through this study I hope to gain a greater understanding of the autistic community and the impact this innovative technique has had on it. You are the vehicle I require in order to gain this understanding. Your cooperation and participation is very much appreciated and valued. If you have further questions please do not hesitate to call me at 265-5694.

Sincerely Yours,

Colleen Trapp



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FAX (403) 282-7269

APPENDIX F

CERTIFICATE OF APPROVAL

by

THE RESEARCH ETHICS COMMITTEE
FACULTY OF SOCIAL WORK

The PROJECT entitled:

THE EXPERIENCES OF PARENTS AND PROFESSIONALS WITH THE
TECHNIQUE OF FACILITATED COMMUNICATION

of COLLEEN TRAPP (ID # 875807) (student)

in the judgement of this Committee, has met The University of Calgary ethical requirements for research with human subjects.

Date

Aug 17, 1992

RM Y
Richard M. Grinnell, Jr., Ph.D.
Research Services, Faculty of Social Work

