REPORT OF THE DEPARTMENT OF REHABILITATIVE SERVICES AND THE DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE SERVICES

## House Joint Resolution 38: A Study of Facilitated Communication in Virginia

TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA



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## **EXECUTIVE SUMMARY**

In the past three years a new method of assisting persons with severe communication disabilities has been introduced in the United States. <u>Facilitated communication</u>, initiated in this country in 1989 by Dr. Douglas Biklen of Syracuse University, has opened the possibility of a new world of interaction and education to individuals who, heretofore, were seemingly unable to participate in many academic and personal communication activities.

The method is still under considerable study, but because of the significant opportunities it holds for people with severe disabilities it has found its way quickly into homes, classrooms, special education programs, and work settings in Virginia and across the country. Because it is still so new and there are as yet few research studies examining the method, there has been some controversy and discomfort with the use of facilitated communication and with the resulting communication it elicits from some individuals who have never had an outlet for communicating their feelings and thoughts before. For these reasons, access to facilitated communication has been limited in some areas while being fully embraced and promoted in others.

The 1992 Virginia General Assembly passed a study resolution, HJR 38, relating to the provision of facilitated communication services in Virginia (Appendix A). The resolution requested that the Department of Rehabilitative Services (DRS) in conjunction with the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) study the viability of and prepare a plan for the development and implementation of facilitated communication programs across the Commonwealth.

In response to this resolution a study task group was convened, directed by DRS and DMHMRSAS with representation by individuals from these Departments as well as representatives of the Department of Education, private and public service providers, consumers and consumer groups, and researchers (Appendix B). The draft document was reviewed by a sample of agencies and organizations representing consumers, service providers, and educational institutions and systems (Appendix C).

The study undertook (1) to examine the viability and validity of facilitated communication as a mode of augmentative communication for people with disabilities, (2) to examine the status of the implementation of facilitated communication in Virginia and in several model programs outside of Virginia, (3) to clarify the issues surrounding facilitated communication, (4) to make recommendations about implementation within Virginia, and (5) to determine the needs for support, study, and inservice and preservice training resources to support the recommendations.

Information was gathered through the exploration of experiences with facilitated communication by individuals with disabilities, their families, and the professionals working with them, a review of the research, descriptive literature and public press coverage on facilitated communication, a cursory survey of service providers in Virginia, and contacts with several programs outside of Virginia that have introduced facilitated communication system-wide. Reviewers of the final draft of this report were invited to submit a written statement of their organizations' positions

on facilitated communication. Comments were received by these reviewers and are reflected in the final draft; but no formal position statements were received.

It is apparent that there are still many unanswered questions about facilitated communication and that ongoing clinical investigation is needed. Programs exist in Virginia which are using this method of communication in unique ways, and research in these programs could provide some answers and models for the implementation of facilitated communication.

There are many implications for the use of facilitated communication, including concerns regarding validation of the process, how it will be paid for, and the fact that facilitated communication is a method for allowing individuals to communicate with others--not a cure or a treatment for their disability. Despite all of these important implications, the most significant may be the change in the quality of an individual's life when facilitated communication allows him or her to communicate with family, peers, and community members. This ability may lead to increased independence for the individual, the power to make his or her own decisions, and the opportunity to be included in family, school, spiritual or religious (e.g., church, temple, mosque), work and community activities that were previously inaccessible to the individual. For these reasons, this work group has accepted Donnellan's (1984, 1992) criterion of least dangerous assumption - that is, "In the absence of conclusive data, educational [and other] decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the student." (Donnellan, 1984, p. 142). In this approach, the danger of not offering this mode of communication is considered much greater than that of offering it and having it fail to meet expectations.

The task group recognized that facilitated communication is not effective for everyone who has a severe speech disability, therefore it is not recommending that the method be mandated. Rather, the proposal recommends that agencies include facilitated communication in their arrays of services and that it be provided within the existing processes of individualized planning for eligible persons.

The following plan is proposed for improving the consistency of application of facilitated communication across the Commonwealth, for addressing the concerns about the use of facilitated communication, and for improving access to information about facilitated communication:

1. The Department of Rehabilitative Services (DRS), Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), and the Department of Education (DOE) should recognize facilitated communication as an augmentative communication method and should direct resources toward its use. Individual agency guidelines should be developed as necessary.

Each agency that serves or provides funding for services for persons with severe disabilities which limit speech should expand its methodologies/services array to include facilitated communication for persons who may benefit from it. Each agency should

develop policies and procedures for making facilitated communication training and services available to its clientele through individual education, treatment, or services plans and within due process provisions. Each agency should address the need for inservice training of personnel and programmatic technical assistance around the provision of facilitated communication training and services.

## 2. The DRS, DMHMRSAS, and DOE should collaborate to provide access to facilitated communication by persons who may benefit from it.

In order to provide continuity of care and appropriate transitioning of services from one setting to another, agencies which have responsibility to provide services for mutual clients should collaborate as necessary to make facilitated communication training and services available for persons who can benefit in as many service and non-service settings as needed. Interagency agreements may be appropriate to promote cooperative planning and services coordination that will maximize all available resources, including facilitated communication, for mutual clients.

## 3. The General Assembly should appropriate funds to support interagency training, research, and information dissemination.

It is proposed that the General Assembly allocate funds of \$100,000 for development and implementation of an interagency demonstration project which would provide training, inservice education, and research which crosses agency and constituency boundaries. A portion of these funds would also enable existing information and referral programs to gather and disseminate information about facilitated communication (Recommendation 6).

The demonstration project would support the development of cross agency/cross discipline teams in each region of the state which could provide training and technical assistance to personnel in state facilities, community habilitation, rehabilitation and vocational programs, educational programs, and residential settings. A statewide cadre of trainers would maintain and expand training to program personnel, families, and other persons in communities throughout Virginia.

The research to be supported would involve program evaluation of the use of facilitated communication in a variety of settings in which the model training is to be provided to determine the efficacy of the training and inservice education programs in terms of increases in utilization of facilitated communication in service settings.

4. The DRS, DMHMRSAS, and DOE should convene an appropriate interagency group to investigate issues that may arise surrounding program placement and eligibility for specific services for individuals as a result of their use of facilitated communication. Interagency guidelines should be developed as appropriate.

An interagency body should be designated to determine and document problems that may arise concerning individuals' eligibility for specific programs, services, and funding sources which may become problematic when improved ability to communicate might suggest a change in functional status. Guidelines will be necessary for how use of facilitated communication shall influence the assessment of an individual's functional status.

5. The DRS, DMHMRSAS, and DOE should work with the State Council on Higher Education to support the inclusion of information and training about facilitated communication in college curricula designed for persons in appropriate human service and special education areas.

Facilitated communication, as a mode of augmentative communication for persons with severe disabilities which limit speech, should be included in the treatment/service repertoire of relevant professionals and paraprofessionals who serve these individuals. Personnel preparation programs in Virginia should appropriately incorporate information about facilitated communication and training in its use.

6. The Secretaries of Health and Human Resources and Education should direct that information about facilitated communication be made available through the existing information and referral, technical assistance, and advocacy programs and systems.

Persons with severe disabilities which limit speech and their families need information and referral on how to and access facilitated communication training and services. In some cases, they may also need advocacy assistance in getting facilitated communication training or services included in individual education, treatment, or service plans. Programs frequently need personnel training and technical assistance to make facilitated communication training and services available to clientele who can benefit.

#### PREFACE

During the 1992 session of the Virginia General Assembly a study resolution was passed relating to the provision of facilitated communication services in Virginia, HJR 38 (Appendix A). The resolution read as follows:

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Rehabilitative Services in conjunction with the Department of Mental Health, Mental Retardation and Substance Abuse Services be requested to study the viability of and prepare a plan for the development and implementation of facilitated communication programs across the Commonwealth. The Departments shall complete their work in time to submit findings and recommendations to the Governor and the 1993 General Assembly as provided in the procedures of the Division of Legislative Automated Systems for processing legislative documents.

In response to this resolution a study work group was convened, directed by the Departments of Rehabilitative Services and Mental Health, Mental Retardation and Substance Abuse Services with representation by individuals from these Departments as well as representatives of the Department of Education, private and public service providers, consumers and consumer groups, and researchers (Appendix B).

The work group acknowledges the assistance of staffs from facilitated communication programs around the country in sharing information about the development of facilitated communication access in their programs; the organizations and agencies that provided support for personnel to work on this study and those that reviewed the drafts of the report; and the consumers who wrote of their experiences and feelings about this method.

The study concluded that while facilitated communication is a new method for assisting persons with disabilities to communicate, the initial research and the reports of personal experience indicate that it offers significant potential for improved quality of life and improved access to academic training for some people. There are existing state and federal regulations that provide for the individualized assessment and provision of appropriate educational, habilitation, and rehabilitation goals and objectives for persons who need them. These regulations require that the needs of people with disabilities be assessed on an individual basis through collaboration by a team including professionals, the family and/or caregivers, and the individual with the disability. Facilitated communication is one method which may be recommended and implemented through this process.

#### CHAPTER I: INTRODUCTION

House Joint Resolution 38 (HJR 38) offered January 15, 1992, directed the Department of Rehabilitative Services (DRS) in conjunction with the Department of Mental Health, Mental

Retardation and Substance Abuse Services (DMHMRSAS) to study the viability of and prepare a plan for the development and implementation of facilitated communication across the Commonwealth.

Federal legislation, including Section 504 of the Rehabilitation Act of 1973, Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), and the Carl Perkins Vocational and Applied Technology Act, mandates that assistive technology and reasonable accommodations be available and accessible for individuals with disabilities for whom these services and accommodations are necessary to participate in major life functions. Facilitated communication is a mode of communication which may be a reasonable accommodation for some individuals with disabilities.

### **Definition of Facilitated Communication**

Facilitated communication is a method of augmentative or alternative communication in which the communicator receives physical assistance from a facilitator to overcome physical and emotional barriers to communication. This facilitator may be a professional, a family member, an aide, a peer, or another member of the community. The facilitator physically supports the arm, hand, or wrist of the communicator enabling the individual to type or point to letters on a key board or other communication device. The facilitator does not assist with the selection of letters, but may help the individual to isolate the index finger and stabilize the hand during pointing or typing, while helping the person pull the hand back after each selection (Crossley, 1990). Eventually the need for facilitation may be decreased, fading the support back to the forearm, shoulder or permitting total independence in communication efforts.

### Background

Introduced into the United States in 1989 by Douglas Biklen of Syracuse University, facilitated communication is a relatively new and little researched method of assisting communication. Originally developed for persons with cerebral palsy, it has been applied to people with autism and other severe developmental disabilities. Facilitated communication has encountered both success and praise, as well as controversy and criticism.

Through the use of facilitated communication certain individuals previously unable to communicate have been able to express themselves. Some individuals are able to use facilitated communication almost instantly and others need as much as two years of introduction to use the method. Once using facilitated communication, some of these individuals communicate at levels far higher than had been thought possible for them.

The successes of facilitated communication are part of the controversy that surrounds the method. The successes of individuals formerly thought to have a mental impairment challenge what is currently believed about autism (Cummins & Prior, 1992). The facilitator's physical contact with the individual causes some observers to question who is moving the communicator's hand. Since facilitated communication is so new, there has been little empirical research

completed to explain and validate its success; however, there is a significant body of anecdotal information documenting its success among individuals with severe communication disorders.

## Focus of the Work Group Study

The work group was charged by the legislature to study the viability of facilitated communication and make recommendations regarding its development and implementation across the Commonwealth. Although not a program in itself, facilitated communication is a method that may be appropriate for use by certain individuals in various settings. The work group study addressed the following questions:

- 1. What research and information exists concerning facilitated communication?
- 2. What is the status of facilitated communication in the Commonwealth of Virginia?
- 3. What are the implications and issues related to facilitated communication for individuals and systems?

### Method of Study

A work group was convened representing the interests of consumers, service providers, private and public organizations, and advocacy and professional groups. The membership of the group contributed knowledge and experience with facilitated communication from both a personal and systems perspective. In addition, the group conducted a review of existing research and knowledge on facilitated communication and initiated a limited statewide survey to obtain an overview of the extent to which facilitated communication is currently used in the Commonwealth.

### Organization of Report

The findings of this study are presented in the four parts of Chapter II. The recommendations are presented in Chapter III.

#### CHAPTER II: FINDINGS

## Part 1: Review of Research and Information

Much of what is written and reported about facilitated communication is in the form of examples, sometimes very dramatic examples, of individuals gaining the ability to communicate through the use of this method. Because of the relative newness of the method (it was

introduced in the United States in 1989) it is understandable that very little in the way of formal research has been done. Frequently, formal research validation lags behind clinical application of new methods of education and treatment (McLean, 1992).

An extensive review of what has been reported about facilitated communication revealed that most articles are found in general professional journals and newsletters and in the popular press. These articles describe the method very generally, provide a brief history of its development, identify the concerns and issues surrounding the method, and provide examples of its success, including the writings of individuals communicating with facilitated communication.

Several studies conducted in Australia, where facilitated communication was first identified, were very mixed in their results (Crossley & McDonald, 1988). The focus of these studies was validation that the communication was that of the communicator and not the facilitator. With little theoretical information about why and how facilitation works, it is difficult to interpret the study results and answer questions such as "Why will an individual work with one facilitator and not another?" or "Why may some individuals learn to communicate with the facilitator's hand withdrawn to their shoulder and others continue to depend on the hand-on-hand approach?"

Biklen reported two studies that he conducted (Biklen, et al. 1991; Biklen & Schubert, 1991) with individuals identified as autistic and having major communication disorders (Appendix C). Although previous formal academic instruction was limited to only a few of the individuals in these studies, use of facilitated communication revealed a previously existing knowledge of words in all but one four year old in each group. The majority of the 22 individuals in one study and 21 individuals in the other study were able to use facilitated communication to make sentences. Biklen reported that the studies demonstrated that facilitated communication is useful with students who previously have had no effective means of communication.

Detractors of facilitated communication contend that more studies need to be done of the method. These critics do not offer studies that indicate facilitated communication cannot be successful but express doubts for a variety of reasons. Cummins and Prior (1992) expressed concern about the lack of diagnostic data presented on the individuals in Biklen's studies. Their concerns, however, seemed to be based on the limited information revealed in journal articles rather than a complete review of the studies. From their review, Cummins and Prior concluded that facilitators appeared to impose their own communication on the participants.

Many critics are concerned that individuals using facilitated communication often appear to be higher functioning than they were previously thought to be (Rimland, 1992). Cummins and Prior (1992) stated that these results represent a challenge to "knowledge coming from almost fifty years" of research on autism. This threat to current beliefs alone seems to cause some to doubt this new method.

In a few instances, negative reaction to facilitated communication was intensified when the inappropriate influence of a facilitator on the information communicated resulted in an accusation of sexual abuse against a parent or caregiver of a facilitating client. Certain disabled populations are more vulnerable to abuse than the general population; however there have been several instances cited in which abuse charges made through facilitated communication have been found to be untrue.

Some researchers feel the fundamental question is whether the facilitator is influencing the process and the communication purported to be generated by the individual (Oswald, 1992). In response to this type of concern, Biklen (1991) identified several qualities that validate the individual's communication: (1) individuals typically make typographical errors unique to them, (2) many communicators produce phonetic spelling unique to them, (3) communicators type phrases or sentences that are unusual and would not be expected from facilitators, and (4) communicators produce content that could not be known to the facilitator.

In a recent preliminary study by Calculator (1992), five students were tested with and without facilitation. During the testing with facilitation, their facilitators were not permitted to hear the questions. Three of the five students performed significantly better when facilitation was used. As a result of the study, Calculator also maintained that it appeared to be very important that the testing environment be a positive one for the students to perform their best.

In what appears to be a credible quasi-experimental study, Szempruch and Jacobson (1992) tested 23 participants classified as severe to profoundly mentally retarded. These participants were shown familiar items and were asked to identify the objects using facilitated communication. Under some conditions the facilitators saw no stimulus, other times they saw a different stimulus from the participant, and at times the same stimulus. No participant was able to describe the object shown to them accurately using facilitated communication. This study could offer no objective support for the use of facilitated communication.

Wheeler, Jacobson, Paglieri, and Schwartz (1992) studied 12 individuals considered to be typing valid communication with facilitation. Pictures of objects were randomly shown to participants and their facilitators. When the same picture was not shown to the facilitator, the participant was unable to type out the correct label for that object. The researchers concluded that these facilitators were determining the responses given by the individual being facilitated.

McLean (1992) stated that studies that provide measures and predictive results will help to establish both an empirical and theoretical base for facilitated communication. He points out, however, that all validation of a method does not have to occur in the laboratory and that the current clinical applications of facilitated communication cannot be ignored.

### Part 2: Survey of Facilitated Communication in Virginia

The work group surveyed agencies and organizations across Virginia which provide

services to people with disabilities to determine the status of facilitated communication (FC) in Virginia. The organizations surveyed included: public and private schools, community services boards, employment services organizations (sheltered workshops, supported employment providers, adult developmental day programs), DMHMRSAS state operated facilities, Woodrow Wilson Rehabilitation Center, and DRS evaluation programs. Because of time constraints, the survey did not include consumers now using facilitated communication or those who may use it in one setting and not others (e.g., at home but not at school or vice versa).

The survey committee used a combination of telephone and mail surveying to obtain a response rate of 65%. Of the 310 organizations who received questionnaires, 201 responded. Responses by type of organization can be seen in Table 1.

TABLE 1

ORGANIZATION	# SURVEYS MAILED	#SURVEY RESPONSES	% OF RETURN
Public Schools	134	101	75%
Private Schools	16	8	50%
CSB's	40	38	93%
ESO's/other	111	45	41%
DMHMRSAS facilities	9	9	100%
TOTALS	310	201	65%

### Prominent findings from the survey:

- The survey respondents reported that 408 school students and 209 individuals served by human services organizations were using facilitated communication. They further reported that 338 school personnel and 150 human services staff were acting as facilitators.
- Of the responding school systems, 48% were using FC with at least one individual. Of the responding human services organizations and agencies, 38% were using it.
- o According to the survey, FC was being used as a communication tool predominantly with persons who have labels of autism and severe/profound mental retardation.
- o 67% of reporting school systems were using FC with elementary school age students and 60% with middle and high school age students. Other reporting human services organizations were using FC predominantly (86%) with adults.
- o Respondents reported that FC was being used in speech program settings and classrooms

for school age individuals and was not being used consistently in other more natural environments (family home, group home) for those same individuals.

- o Small numbers of individuals per organization are trained to use FC with their consumers. Training that has occurred in the use of FC ranges from attending 3-4 day seminars at Syracuse University to individuals being self taught as facilitators. Many facilitators have attended 1-2 day seminars provided through various organizations.
- o FC is not consistently available across the Commonwealth.

43% of responding organizations were using FC 57% of responding organizations are not using FC

- O According to this limited survey, a total of 617 individuals with disabilities are currently using FC. The number of individuals who could benefit from FC is unknown.
- According to the survey, a total of 726 professional staff have participated in some level of training. The majority of individuals acting as facilitators are paid professionals. Families were not surveyed, consequently, the survey results show that FC is used predominantly by professionals.
- o Training in the use of FC is needed across the Commonwealth. Survey respondents indicated that 1,688 people would access training if it were made available.

Tables 2 and 3 present the reported distribution of use across disability labels.

#### Part 3 - Examples of Current Use Outside of Virginia

Contacts were made to three programs outside of Virginia which have implemented facilitated communication on a system wide basis to determine the status and success of various facilitated communication programs. The programs contacted were: the Facilitated Communication Institute at Syracuse University, the Central Susquehanna (PA) Intermediate Unit (a public school special education program), and the Vermont Facilitated Communication Project (a program of the state mental health agency).

Currently, the Facilitated Communication Institute is the major center of study and training in facilitated communication in the United States. It has a cooperative agreement with the Syracuse Public Schools to provide facilitated communication services, and it provides the primary source for training in this method nationally. By the summer of 1992, over 2,000 parents, teachers, speech-language pathologists, and others had received training to use and teach facilitated communication at this institute (Morton, 1992).

TABLE 2
EXTENT OF USE BY DISABILITY LABEL

Disability Labels	Frequency Indicated*	% of Use
Schools - n = 48		
Autism Severe/profound Mental Retardation Moderate Mental Retardation Mild Mental Retardation Traumatic Brain Injury Cerebral Palsy Other  Human Services Organizations - n=35	33 24 19 4 5 15 6	69 % 66 % 40 % 8 % 10 % 31 % 13 %
Autism Severe/profound Mental Retardation Moderate Mental Retardation Mild Mental Retardation Traumatic Brain Injury Cerebral Palsy Other	31 24 12 3 0 9	89 % 69 % 34 % 6 % 0 % 25 % 14 %

<sup>\*</sup> Indicates the number of organizations who checked each disability, not the actual number of people in each category.

TABLE 3
SETTINGS WHERE FC WAS REPORTED USED

Settings	Frequency	% of Use	
Schools - $n=48$	·		
Classroom Family home Work site Speech program Community residence	29 16 5 35	60 % 33 % 10 % 73 %	
(group adult home) Living unit/residential facility Other	2 2 1	4% 4% 2%	
Human Service Organizations - n=35			
Classroom Family home Work site Speech program Community residence	6 8 21 7	17 % 23 % 60 % 20 %	
(group adult home) Living unit/residential facility Other	12 6 4	34% 17% 11%	

<sup>\*</sup> Indicates the number of respondents who checked each disability, not the actual number of people using FC in each setting.

In Vermont in 1990, the Facilitated Communication Project was begun through the state mental health agency. Its purpose was to train persons to use facilitated communication and to provide support and networking for those using the method throughout the state and region. This program has made great strides in offering this method of communication to individuals throughout Vermont, and has developed some unique approaches to training, including the development of teams of facilitators, support networks, and a newsletter to provide ongoing information and updating about facilitated communication. The Central Susquehanna Intermediate Unit in Pennsylvania has initiated facilitated communication in the public school systems it serves, providing training and a support network for facilitators in the public schools in that area.

In addition to the United States and Australia, facilitated communication is being used in Canada, England, Iceland, Finland, Germany, Italy, India, Greece, New Zealand, Sweden, Denmark and Israel.

### Part 4 - Implications of the Use of Facilitated Communication

While facilitated communication remains a controversial technique, the implications are significant and wide spread. First and foremost, the appropriate use of facilitated communication has the potential to change significantly the lives of individuals with disabilities and how society views those individuals. Perceptions of individuals who are able to use facilitated communication often must change - from a view of the individual as a retarded, low functioning, non-interactive individual to seeing him or her for the first time as a sensitive, intelligent, social being who desires to interact with peers and to play a part in everyday life. Facilitated communication can open doors for these individuals to interact with the world in which they live and allow those in that world to view them as more competent, intelligent, and deserving of being treated as normal human beings. (See writings of facilitated communication users, Appendix F).

The availability of facilitated communication has important implications in many other aspects of individuals' lives and for the population of the Commonwealth in general. Some of the implications and issues germane to this mode of communication are discussed as follows:

Freedom of Speech. The existence of facilitated communication raises many questions regarding the implications of providing or not providing this form of communication to individuals. If facilitated communication is the only means through which an individual may be able to communicate in his or her community, is denying access to it comparable to denying a person access to freedom of speech? Viadero (1992) has said that "To decline to use facilitated communication with students for whom it works would be 'not unlike taking a normal child and putting a gag over his mouth and handcuffing his hands behind him.'" The question must be posed: "Does a program, school, agency, or even the Commonwealth have the obligation to continue facilitated communication once it is started with an individual?" If it is denied to an

individual, is it also denying that person freedom of speech?

Accessibility. The accessibility of facilitated communication training for individuals who wish to learn the technique is important. The Vermont Facilitated Communication Project reports that the most effective use of this method occurs when multiple service providers and family members are trained to use facilitated communication with an individual (Ashe, 1992). If this is the case, then quality training should be readily available to human service workers, families, caregivers, and other members of a person's community who desire to be trained to interact with the person who has the disability in communicating.

It was the finding of this work group that there are already mechanisms in place for determining the appropriateness of facilitated communication for an individual and for making it available through individualized educational, rehabilitation, or service plans. Further legislation is not necessary to make it available, but further access to training at all levels is needed and access to the various support services and accurate, up to date information is needed.

<u>Financial</u>. There are many financial implications of providing training and facilitated communication to individuals with disabilities. In the cases where this method is successful, it is likely that individuals will have an increased capacity to communicate with all peers. This can lead to opportunities for vocational training, employment, and other personal financial gains for the individual.

The promotion of facilitated communication and accessibility to training will, however, have associated costs. The initial and ongoing training of service providers (group home workers, school personnel, family members, etc.) will require training dollars. The greater financial implication is, however, when individuals gain a voice that can be heard and validated, they may express that they wish to be in different types of programs or settings than those in which they are currently placed. Additional mainstreamed or normalized programs, which in the long run may prove to be cost effective, may initially cost more than current programs.

In some settings, it may be appropriate for one person to be assigned to an individual as that person's facilitator, much as a personal attendant or an interpreter is now assigned to an individual. The accompanying costs of such a setting could be very high. In most cases, however, the recommendation that various people already in the individual's environment be trained to facilitate communication would alleviate the need for a single individual to be available to the person.

Eligibility. With some individuals, the introduction of facilitated communication will radically reshape how society sees their abilities and skills. They will be better able to communicate their thoughts, and their intelligence and capabilities may be more accurately evaluated. In the cases where individuals' intelligence levels are significantly upgraded, this opens the door to the possibility that some individuals may no longer be eligible for mental retardation services. It is apparent that, while intellectual skills may be higher than previously thought, many of these individuals still are significantly disabled. This scenario could potentially

result in the denial of services to a group of individuals whose functional skill levels still will not allow them to operate independently in society. This may necessitate a revamping of the eligibility criteria for such programs as Mental Retardation Services - an issue which has implications for federal as well as state programs.

There is the issue, too, of setting parameters for the application of psychological and educational testing procedures with facilitated communication. It will be critical to establish standard guidelines for testing, as well as guidelines for how and when life change decisions may be made based on such testing.

Legal. There are a number of legal issues that arise because of the introduction of facilitated communication. Some of these arise because of the types of messages that individuals produce (such as allegations of abuse), some arise from the individual's apparently increased communication and intellectual abilities. Issues such as legal competency, the acceptance and application of legal testimony via facilitated communication, and again, the appropriateness of making life change decisions via facilitated communication must still be studied and guidelines written.

Training. If facilitated communication is to be provided in the most appropriate and careful manner, the availability of quality training programs which assume a systems approach to service delivery will be important. Critical to this training will also be the inclusion of guidelines for ethical application of facilitated communication and quality management. Three types of training have been identified as necessary: training of direct service providers, training for families and consumers, and training for peer and other community members.

Training for direct service providers could be provided through "train the trainer" models, mentoring, and inservice professional training programs. Elements of existing programs which are considered best practices could be defined to ensure the highest quality of training. It is essential that a core group of "master" trainers be developed in the state to provide ongoing training to other groups and to provide consultation and ongoing support. The Developmental Language Instruction training model piloted by the DOE could provide a model for development of this training package.

Training for families, consumers, and community members should be targeted as an intact package. Evidence from the Vermont Facilitated Communication Project indicates that families, consumers, providers, and other individuals in a person's environment trained as a team is the most effective model and helps to ensure that issues that arise can be resolved in a holistic manner. Families and caregivers are viewed as critical to the successful use of this method by individuals, and the provision of team training helps to promote this linkage. There are existing community resources which could be accessed to facilitate such training, including Parent Resource Centers, Parent Education/Advocacy and Training Centers, Technical Assistance Centers, and the Virginia Autism Resource Center.

Emotional Support. Individuals involved in working with persons using facilitated communication report that most of these individuals need emotional support. People with a

disability who use facilitated communication often report that they are angry with the way they have been treated, that they are having difficulty coping with their disability, and that they want to learn how to interact with others. Often counseling and other forms of emotional support are required to enable the person to learn to address these issues. This type of support is often not available to individuals with disabilities. Training counselors and therapists who can work with individuals who use facilitated communication will be important.

Family members and service providers who interact with an individual with autism or other disability who begins to use facilitated communication also report the need for emotional support. Because facilitated communication often changes how family members and service providers perceive the individual with a disability, they often report high levels of guilt about their previous perceptions and interaction styles. Counseling and emotional support is needed to assist family members and service providers as they make the transition from seeing the individual as a person with autism or another type of disability to a more competent, intelligent individual.

<u>Information Dissemination</u>. The dissemination of current and accurate information about such a new method is important in promoting access and the provision of quality services. There are existing informal and formal structures for information dissemination throughout the state. Informal structures include peer and community networking and "word of mouth" sharing by service providers, families, and community members.

Formal structures include private and public sector information and referral resources, including United Way information and referral agencies, the Virginia Assistive Technology System (VATS) operated through DRS, the federally funded Technical Assistance Centers, Parent Resource Centers, the Virginia Autism Resource Center, and others. These information and referral resources need access to extensive and continuously updated information related to facilitated communication and appropriate resources and contacts for people interested in this service.

Research. It is apparent that there are still many unanswered questions about facilitated communication and that ongoing clinical investigation is needed. Programs exist in Virginia which are using this method of communication in unique ways, and research in these programs could provide some answers and models for the implementation of facilitated communication.

There are many other implications for the use of facilitated communication, including concerns regarding validation of the process, how it will be paid for, and the fact that facilitated communication is a method for allowing individuals to communicate with others--not a cure or a treatment for their disability. Despite all of these important implications, the most significant may be the change in the quality of an individual's life when facilitated communication allows him or her to communicate with family, peers, and community members. This ability may lead to increased independence for the individual, the power to make his or her own decisions, and the opportunity to be included in family, school, spiritual or religious (e.g., church, temple, mosque), work and community activities that were previously inaccessible to the individual. For

these reasons, this work group has accepted Donnellan's (1984, 1992) criterion of least dangerous assumption - that is, "In the absence of conclusive data, educational [and other] decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the student." (Donnellan, 1984, p. 142). In this approach, the danger of not offering this mode of communication is considered much greater than that of offering it and having it fail to meet expectations.

#### RECOMMENDATIONS

Facilitated communication is one method, across a continuum of services and programs, that can be used to augment and enhance communication for certain individuals with developmental disabilities. As such, some of the individuals who have benefitted from it have demonstrated communication and cognitive abilities far beyond previous expectations. Since communication is the foundation for all major life functions, and facilitation opens doors for some individuals who heretofore have been unable to exercise their right to freedom of speech, access becomes a critical issue.

Federal legislation, including Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and the Carl Perkins Vocational and Applied Technology Act, mandates that assistive technology services and reasonable accommodations be available and accessible for individuals with disabilities for whom these services and accommodations are necessary to participate in major life functions. Facilitated communication is a method of communication which, as a technique, may be a reasonable accommodation and/or a necessary related service for some individuals with disabilities.

There is currently inconsistency and informality in the use of facilitated communication throughout Virginia. Statewide access to facilitated communication can be described as fragmented, at best. This work group proposes a systems approach to promoting access to facilitated communication which would capitalize on existing community resources and enhance overall service delivery in a holistic, comprehensive manner, while acknowledging continuing concerns about the need for further validation research and study. This systems approach can be accomplished best through addressing issues of information and referral, training resources, and ongoing support and research.

The task group recognized that facilitated communication is not effective for everyone who has a severe speech disability, therefore it is not recommending that the method be mandated. Rather, the following proposal recommends that agencies include facilitated communication in their arrays of services and that it be provided within the existing processes of individualized planning for eligible persons.

In response to the resolution by the General Assembly, the following plan is proposed for improving the consistency of application of facilitated communication across the

Commonwealth, for addressing the concerns about the use of facilitated communication, and for improving access to information about facilitated communication:

1. The Department of Rehabilitative Services (DRS), Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), and the Department of Education (DOE) should recognize facilitated communication as an augmentative communication method and should direct resources toward its use. Individual agency guidelines should be developed as necessary.

Each agency that serves or provides funding for services for persons with severe disabilities that limit speech should expand its methodologies/services array to include facilitated communication for persons who may benefit from it. Each agency should develop policies and procedures for making facilitated communication training and services available to its clientele through individual education, treatment, or services plans and within due process provisions. Each agency should address the need for inservice training of personnel and programmatic technical assistance around the provision of facilitated communication training and services.

2. The DRS, DMHMRSAS, and DOE should collaborate to provide access to facilitated communication by persons who may benefit from it.

In order to provide continuity of care and appropriate transitioning of services from one setting to another, agencies which have responsibility to provide services for mutual clients should collaborate as necessary to make facilitated communication training and services available for persons who can benefit in as many service and non-service settings as needed. Interagency agreements may be appropriate to promote cooperative planning and services coordination that will maximize all available resources, including facilitated communication, for mutual clients.

3. The General Assembly should appropriate funds to support interagency training, research, and information dissemination.

It is proposed that the General Assembly allocate funds of \$100,000 for development and implementation of an interagency demonstration project which would provide training, inservice education, and research which crosses agency and constituency boundaries. A portion of these funds would also enable existing information and referral programs to gather and disseminate information about facilitated communication (Recommendation 6).

The demonstration project would support the development of cross agency/cross discipline teams in each region of the state which could provide training and technical assistance to personnel in state facilities, community habilitation, rehabilitation and vocational programs, educational programs, and residential settings. A statewide cadre of trainers would maintain and expand training to program personnel, families, and other

persons in communities throughout Virginia.

The research to be supported would involve program evaluation of the use of facilitated communication in a variety of settings in which the model training is to be provided to determine the efficacy of the training and inservice education programs in terms of increases in utilization of facilitated communication in service settings.

4. The DRS, DMHMRSAS, and DOE should convene an appropriate interagency group to investigate issues that may arise surrounding program placement and eligibility for specific services for individuals as a result of their use of facilitated communication. Interagency guidelines should be developed as appropriate.

An interagency body should be designated to determine and document problems that may arise concerning individuals' eligibility for specific programs, services, and funding sources which may become problematic when improved ability to communicate might suggest a change in functional status. Guidelines will be necessary for how use of facilitated communication shall influence the assessment of an individual's functional status.

5. The DRS, DMHMRSAS, and DOE should work with the State Council on Higher Education to support the inclusion of information and training about facilitated communication in college curricula designed for persons in appropriate human service and special education areas.

Facilitated communication, as a mode of augmentative communication for persons with severe disabilities which limit speech, should be included in the treatment/service repertoire of relevant professionals and paraprofessionals who serve these individuals. Personnel preparation programs in Virginia should appropriately incorporate information about facilitated communication and training in its use.

6. The Secretaries of Health and Human Resources and Education should direct that information about facilitated communication be made available through the existing information and referral, technical assistance, and advocacy programs and systems.

Persons with severe disabilities which limit speech and their families need information and referral on how to and access facilitated communication training and services. In some cases, they may also need advocacy assistance in getting facilitated communication training or services included in individual education, treatment, or service plans. Programs frequently need personnel training and technical assistance to make facilitated communication training and services available to clientele who can benefit.

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<sup>\*</sup>All references and a demonstration videotape are available through the Commissioner's Office, Dept. of Rehabilitative Services. Contact Sarah Jenkins, Legislative Liaison, telephone (804) 367-0365.

## **APPENDICES**

Appendix A - HJR 38

Appendix B - Facilitated Communication Task Group

Appendix C - List of Reviewers

Appendix D - Review of Research Studies

Appendix E - Survey Questionnaire

Appendix F - Samples of Writing of Facilitated
Communication Users

Appendix G - Annotated Bibliography

## 1992 SESSION

LD4118136

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#### HOUSE JOINT RESOLUTION NO. 38

Offered January 15, 1992

Requesting the Department of Rehabilitative Services in conjunction with the Department of Mental Health. Mental Retardation and Substance Abuse Services to develop a plan for the development and implementation of facilitated communication programs across the Commonwealth.

Patrons—Brickley, Marshall, Parrish and Rollison; Senator: Colgan

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## Referred to the Committee on Rules

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WHEREAS, each year many children are born suffering from a variety of physical and neurological illnesses such as cerebral palsy, mental retardation, Down's syndrome, and autism, all of which severely limit or prohibit communication with others: and

WHEREAS, until recently, most of these children were labeled as mentally incapable of communicating because of extremely low IQ levels; and

WHEREAS, autism, primarily, is characterized as an inability to feel love or form social attachments, a lack of self-awareness, mental retardation, difficulty understanding speech, and an inability to grasp concepts or symbols; and

WHEREAS, research over the years has found that, if enabled, autistic children who 21 were previously labeled as unteachable can read, write, calculate, and do schoolwork 22 appropriate to their age; and

WHEREAS, although trapped by their lack of physical and mental control over bodily 24 direction, many autistic and other such persons have been allowed to converse with others through a method called facilitated communication; and

WHEREAS, through physical and emotional support from a facilitator, an individual 27 learns to use a communication aid or a keyboard for expression; and

WHEREAS, the facilitator, whose assistance may eventually be phased out or used 29 minimally, provides support of the person's hand or arm to allow the person to overcome 30 various manual problems or impulsive movements and to indicate a letter or other selection; and

WHEREAS, research is showing that, although many persons communicating with this 33 method have had no previous education in reading and writing, many have shown unexpected literacy skills, indicating that their disability is not one of cognitive or receptive difficulties but one of difficulty in carrying out motor movements and hand function; and

WHEREAS, such developments are changing the way persons with such disabilities are 37 treated and regarded; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Rehabilitative Services in conjunction with the Department of Mental Health, Mental 40 Retardation and Substance Abuse Services be requested to study the viability of and prepare a plan for the development and implementation of facilitated communication 42 programs across the Commonwealth. The Departments shall complete their work in time to submit findings and recommendations to the Governor and the 1993 General Assembly as provided in the procedures of the Division of Legislative Automated Systems for processing legislative documents.

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## APPENDIX B FACILITATED COMMUNICATION TASK GROUP

Linda Meyer, Ph.D., Chair Woodrow Wilson Rehabilitation Ctr. DRS Linda Veldheer, D.P.A. DMHMRSAS Coordinator

Judy Bailey Accutek Assemblies, Inc. Manassas Donald Oswald, Ph.D. Dept. of Psychiatry MCV

Sandra Ball
Dept. of Education

Sue Ravlin Speech-Language-Hearing Assoc. of Virginia

Gerry Edelstein Henrico Co. Public Schools

Terrie Silverman Greater Richmond Autism Support Programs

Marjorie Garren Southside Va. Training Ctr. DMHMRSAS

J. R. Smith
Parent of autistic child
Central Virginia Branch,
Autism Society of America

Kathy Hayfield
Office of Employment Services
DRS

Jan Spiers Region 10, CSB Charlottesville

Gail Honea, Ed.D. Quality Assurance Unit DRS

> Betty Thompson Parent of autistic child Chesterfield

Gail Mayfield
Grafton School &
Virginia Autism Resource Ctr.
Berryville

Kathy Trossi
Educational Services Mgr.
DRS

Michael McCormick
Early Childhood Special Educ. TAC 4
VCU

#### APPENDIX C

### LIST OF REVIEWERS OF DRAFT REPORT

American Speech-Language-Hearing Assoc.

Paula Castagna, Speech Pathologist

Gayle Daly Special Education Dept. Lynchburg City Schools, VA

Easter Seal Society of Virginia

Facilitated Communication Institute Syracuse University Syracuse, NY

Martha E. Snell, Ph.D. School of Education UVA

Vermont Facilitated Communication Project Barre, VT

Virginia Association for Retarded Citizens

Virginia Board for People with Disabilities

Virginia TASH (The Association for Severely Handicapped)

#### APPENDIX D

#### Facilitated Communication Studies

Biklen, D., Morton, M. W., Saha, S. N. Duncan, J., Gold, D., Hardardottir, M., Karna, E., O'Connor, S., and Rao, S. (1991). I'm not autistic on the typewriter. Disability, Handicap & Society, (6) 3 p. 161 - 180.

In this study, 22 individuals with autism were exposed to facilitated communication for over 12 months. The group included preschool, elementary, middle school, high school and high school/community work site members. The students had major communication disorders, either being mute or using echolalic expressions. Research was conducted using participant observation and videotaping of students and teachers. Students were observed (1) in normal classroom situations not involved with facilitated communication; and (2) during speech therapy and academic instruction using facilitated communication. Examples of student work were examined and speech and academic instruction was videotaped. All students were observed by at least two observers at different times. Videotapes were examined by at least two different researchers.

#### Results

- o All but one of the 22 demonstrated literacy within the first 11 months of this study.
- o Two students had not produced sentences.
- o Nineteen have produced sentences but two only use very simple sentences.
- o Each of the students demonstrated unexpected cognitive and receptive abilities.
- o None of the students had been instructed in anything except the most basic math or reading skills (money denominations, some sight words) yet many could do math and read.
- o In a number of instances students who had been assumed to be severely intellectually disabled revealed grade level literacy and numeracy skills.
- o 12 students have demonstrated an ability to do some academic work appropriate to their grade.

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

In this study, 21 students were selected by their facilitated communication teachers. The criteria for selection was that the students were identified as autistic and had major communication disorders including being mute or using echolalic speech.

The students were observed using facilitated communication in the classroom and/or in speech therapy sessions; they were also observed in the classroom or speech therapy not using facilitated communication. Typed student output was collected and some sessions were videotaped.

The data collections lasted over six months. During that time the students were observed by at least two observers at different times. Each video tape was viewed by two or more researchers.

#### Results

Prior to being introduced to facilitated communication few of the 21 students had had any formal instructions in reading. The typing revealed that all but one four year old student had a knowledge of words and 17 used facilitated communication to create sentences. The study demonstrated that facilitated communication is useful with students who previously have had no effective means of communication.

## FACILITATED COMMUNICATION

In January, the General Assembly passed House Joint Resolution No. 38 requesting the Department of Rehabilitative Services and the Department of Mental Health, Mental Retardation and Substance Abuse Services to study the viability of and develop a plan for the development and implementation of Facilitated Communication (FC) programs across the Commonwealth.

Please help the task force gather information about the current usage of Facilitated Communication in Virginia by responding to this questionnaire. The information you provide will be kept strictly confidential and used in the report to the General Assembly in aggregate form only. Identities of respondents will be protected.

1.	Check the type of organization you represent?
	Public School Private School Community Services Board Long term MH/MR Facility Employment Service Organization (rehab facility/supported employment) Other
2.	Is FC being used within your organization? yes no
	If your answer to #2 is NO, skip to #10
3.	How many staff are using FC as a communication tool with people with disabilities?
4.	List the various job roles/relationships of the facilitators to the users with disabilities?
5.	How many staff from your organization have been trained to use FC?
	Describe the training staff have attended (length of training, sponsoring organization, individual trainer, training modality)
6.	How many individuals with disabilities are using FC?
7.	Check the disability labels of the users of FC?
	Autism Profound Mental Retardation Severe Mental Retardation Moderate Mental Retardation Mild Mental Retardation Traumatic Brain Injury Cerebral Palsy Other Other

8.	Check age ranges of users with disabilities
	Pre-school Elementary Middle/High School Adult
9.	Check the settings in which FC is currently being used?
	classroom family home work site speech program community residence(group home, adult home) living unit in a long term care facility recreational setting other other
	<u>-</u>
10.	If training were made available, how many staff would you like to have attend?
10.	If training were made available, how many staff would you like to have attend?
10.	If training were made available, how many staff would you like to have attend?
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10.	If training were made available, how many staff would you like to have attend?
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Thank you for your response!

Questions? 804-367-0254

#### APPENDIX F

### WRITING SAMPLES FROM FACILITATED COMMUNICATION USERS

#### C.C. - Adult FC user

Response to the question, "What has facilitated communication meant to you and your life?"

## Eight year old boy diagnosed with autism and mental retardation - communicating with his mother via facilitated communication

Mother: How does it feel to be able to facilitate?

Stephen: It makes me happy that I can tell people things.

Mother: Has it changed your life?

Stephen: Yes. Mother: How?

Stephen: It helps people to know I'm smart.

Mother: Do you have anything to say to the people who will read this?

Stephen: You should teach all autistic kids to type so they can talk to their mommys like me.

Mother: Anything else you want to say?

Stephen: Just get teachers to type at school. To talk is to die for.

Mother: Are you done?

Stephen: Yes. yes.

Thirteen year old diagnosed with autism and mental retardation, using facilitated communication with his mother (this interchange began on a letter board, but switched to a Canon communicator because he had so much to say).

Mother:

What do you think about using facilitated communication?

Matthew:

It has made my life better because now I can talk to you and my friends. Now that I can type you know I am smart and that I can read so you don't treat me

like a baby as much.

Mother:

Do you think I treat you like a baby still?

Matthew:

You stillpatronize me too much so I need other people to talk to besides you. It is good to have facilitated communication. I opens you up to my strengths instead of my weaknesses and lets you know I'm not dumb.

Mother:

Would you like to say anymore?

Mathew:

(on Canon) i know that imhandicapped but im not worthless i need a lot of help to type i hope people learn to type with me so i can talk to more people and let them know i am just like them except i cannt talk and i cant control my body will everyone learn how to type someday i need a lot of people around to help me and support my hand to type some people sstill think you are moving my hand so the more people who learn to type with me the more the majority of people will know im a smart tells them i need a lot of support to type and i need a lot of people to learrn how to help me so can talk to everyone tell legislators people like me should get support so we can talk like people when i use my voice people assume im stupid since i cantt control my voicce or my body when i talk people thin im retarded since i sound so forshn foreign to mostp still im not really retarded although i am handicapped by my audism im tie\red now it takdes a lot of energy to typdde so much so ill quit now say you are proud of me for typing so much stop stopwill you kiss me ilove you mom for typing to nmmtoday will we type tomorrow i love to type but i need the support from ynou

#### APPENDIX G

## ANNOTATED BIBLIOGRAPHY ON FACILITATED COMMUNICATION

The following is a listing and brief review of several articles which describe facilitated communication and address the concerns about and successes of this method. These articles are available to reviewers of the report upon request.

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

This article describes Biklen's research on facilitated communication at the DEAL Communication Centre in Melbourne, Australia. Biklen observed 21 people classified as having autism using facilitated communication. Included in the article is a description of methodology and literature review on autism and communication with focus on how facilitated communication fits in the context of this literature.

Biklen, D. (1992) Typing to talk: Facilitated communication.

<u>American Journal of Speech-Language Pathology</u>. 1(2), 15-17, 21-22.

This "Second Opinion" article presents Biklen's viewpoint on facilitated communication, along with a response to the article by Stephen Calculator, of the University of New Hampshire. This issue also contains a third opinion by James McLean, of the University of Kansas, who provides analysis of the opinions of Biklen and Calculator.

Biklen, D. et al (1992) Facilitated communication:
Implications for individuals with autism. Topics in Language Disorders, 12(4), 1-28.

This article appears in a TLD issue devoted exclusively to facilitated communication. Included in this article are background of autism and related communication disorders, the facilitated communication method, qualitative examination and validation of facilitated communication, and literacy implications.

Biklen, D. (1991) "Ask the Experts" talks with Douglas Biklen.

The Advocate, Spring 1991.

In this article, Biklen responds to some of the most frequently asked questions regarding facilitated communication, including issues of cognition, integration and future implications.

Biklen, D. (1991) I AMN NOT A UTISTIVC OH THJE TYPE ("I'M NOT AUTISTIC ON THE TYPEWRITER").

Introductory videotape on techniques of facilitated communication, available through Syracuse University.

Calculator, S. (1992) Perhaps the emperor has clothes after all: A response to Biklen.

<u>American Journal of Speech-Language Pathology</u>. 1(2), 18-20, 23-24.

This "Second Opinion" article is a response by Calculator to Biklen's "Typing to Talk" article. Calculator challenges that reports of successful use of facilitated communication lacks empirical data, relying on anecdotal accounts instead. Calculator suggests that further research is necessary to determine what specific factors are instrumental in reporting client gains using this method. Other validation issues are outlined in the article as well.

Crossley, R. (1988) Unexpected communication attainments by persons diagnosed as autistic and intellectually impaired.

Unpublished paper presented to the International Society for Augmentative and Alternative Communication, Los Angeles, CA.

Crossley describes her experiences with individuals using facilitated communication.

Crossley, R. (1990) Communication training involving facilitated communication. Paper presented to the Annual Conference of the Australian Association of Special Education.

In this paper, Crossley examines difficulties associated with severe speech impairments, and reports on the successful implementation of facilitated communication.

Crossley, R. & Remington-Gurney, J. (1992). Getting the words out: facilitated communication training. <u>Topics in Language Disorders</u>. 12(4), 29-45.

This article appears in the TLD issue devoted exclusively to facilitated communication. The article focuses on use of facilitated communication with individuals at the DEAL Communication Centre, practical considerations, and validation issues.

Crossley, R. (1992) Getting the words out: case studies in facilitated communication training.

<u>Topics in Language Disorders</u>, 12(4). 46-59

In this article, Crossley presents case studies where facilitated communication training is successfully used with clients who were initially believed to be intellectually impaired due to the absence of speech. Crossley emphasizes the importance of assessing an individual's degree of impaired hand function when assessing his/her speech and language needs. The three case studies examined in the article have been judged to be respectively prfoundly, severely, and moderately intellectually impaired.

Crossley, R. & McDonald, A. (1980) Annie's Coming Out. New York: Penguin.

In this book, Crossley and McDonald describe the struggle they waged against the St. Nicholas Institution in Melbourne, Australia, to win freedom for Annie McDonald, an individual with cerebral palsy. Crossley describes her early work using the method she has come to call facilitated communication.

Crossley, R. Lending a hand: A personal account of the development of facilitated communication training. (1992) <u>American Journal of Speech-Language Pathology</u>, 1(3), 15-18.

In this article, Crossley presents a "world view" of her early encounters with facilitated communication training. Crossley presents an historical perspective of the development and use of facilitated communication in Australia, and offers her interpretations of its theoretical and practical implications.

Donnellan, A., Sabin, L. & Majure, L. (1992) Facilitated communication: Beyond the quandary to the questions. <u>Topics in Language Disorders</u>, 12(4). 69-82

This article appears in the TLD issue devoted exclusively to facilitated communication and addresses issues of skepticism over the phenomenon of it, with specific emphasis on variables in research which have come under fire (touch, attunement, and the written word). This article surmises that while there is a strong basis for skepticism, that research can and should continue as a means to investigate and challenge current thinking about the syndrome of autism and other developmental disabilities.

Goodwin, M.S. & Goodwin, T.C. (1969) In a dark mirror. Mental Hygiene, 53(4), 550-563.

This article was written prior to recognition of facilitated communication as a means for people with autism to communicate. In the late 60's, two pediatricians, Mary and Campbell Goodwin, used the Edison Response Environment (talking typewriter) to enable students with autism to communicate.

Jacobson, J. & Mulick, J. (1992) Behavior modification and technologies: Speak for yourself, or...I can't quite put my finger on It! <u>Psychology in Mental Retardation and Developmental Disabilities</u>, 17(3), 3-7.

This article reports on the questions raised when any training approach, especially an unconventional one such as facilitated communication, discourages serious evaluation and study.

McLean, J. (1992) Facilitated communication: Some thoughts on Biklen's and Calculator's interaction. American Journal of Speech-Language Pathology. 1(2). 25-27.

This "Second Opinion" article presents McLean's analysis of the procedures of facilitated communication described by Biklen and the counterpoint by Calculator that these procedures lack a theoretical basis. McLean offers credence to both sides of this controversy, stressing the need for empirical validation, but also suggesting that clinicians and behavioral scientists should not dismiss this unconventional technique.

Oppenheim, R. (1974) Effective Teaching Methods for Autistic Children. Springfield, Illinois: Charles C. Thomas Publishers.

In this book Oppenheim describes her use of hand-over-hand support to assist students with autism to accomplish handwriting. This book is considered a forerunner of what we now call facilitated communication. Oppenheim discovered that with modest physical support a number of her students, including her own son, were able to communicate effectively.

Prior, M. & Cummins, R. (1992) Questions about facilitated communication and autism.

<u>Journal of Autism and Developmental Disabilities</u>. 22(3), 331-338.

This article is a validation of facilitated communication, which is based on over eight years experience with the technique by Australians, including Rosemary Crossley. The article sharply criticizes Biklen's promotion of the technique as "media hype" and offers an empirical critique of information presented to government review panels in Australia.

Rimland, B. (1990) Autistic crypto-savants. Autism Research Review International, 4(1), 3.

In this article, Rimland writes about the communication abilities of some students he has observed. While he has not specifically identified the method of facilitated communication, there are parallels between his findings and those that have been made using facilitated communication techniques.

Rimland, B. (1992). A facilitated communication 'Horror story.' <u>Autism Research Review International</u>, 6(1), 7-8.

This article reports on a case of alleged parental sexual abuse by a 29-year-old Australian woman via facilitated communication. After the woman became despondent when she was taken away from the family from who she reportedly asked to escape, the government of Australia investigated the case under four separate conditions to determine the degree of facilitator influence. It was concluded that the woman could not communicate independently and that the facilitators were influencing her communication. The family regained full custody of their daughter.

Rimland, B. (1992) Facilitated communication: Now the bad news. <u>Autism Research Review International</u>, 6(1), 3.

This commentary reveals a number of "horror stories" from parents about their experiences with facilitated communication and alleged sexual abuse charges. In each reported case, the children were removed from their homes immediately, without evidence to support the charges. Some parents were even incarcerated without the benefit of a hearing. While Rimland stresses the favorable results of using facilitated communication, he stresses the consequences of its misuse and the potential for inadvertent facilitator influence.

Silliman, E. (1992) Three perspectives of facilitated communication: Unexpected literacy, Clever Hans, or enigma? <u>Topics in Language Disorders</u>, 12(4), 60-68

This commentary appears in the TLD issue devoted exclusively to facilitated communication and offers three perspectives on the phenomenon of it: (1) the belief in the "Clever Hans" effect, or an unintentional influence of research, clinical interventions, and educational approaches; (2) the belief in unexpected literacy and competency; and (3) those who consider it plausible, although an enigma.

Spake, A. (1992). It is like wishing I could be normal. The Washington Post. May 31, 1992.

This article reports on the successful classroom use of facilitated communication at Poplar Tree Elementary School in Fairfax County, Virginia, by teacher Kathy Milam.

Vermont Facilitated Communication Project (1992) New England Newsletter on Facilitated Communication, 1(1), March '92.

A newsletter established to provide a vehicle for sharing information about facilitated communication. The networking newsletter is provided through the VFCP in Barre,

Vermont, and includes articles regarding case studies, most frequencly asked questions, technology tips, validation issues, and announcements of upcoming events related to facilitated communication.

Viadero, D. (1992) Keyboard helps autistic youths find their voices, advocates say. <u>Education</u> Week, 11(38). June 10, 1992.

This article focuses on the successful use of facilitated communication with students at Grafton School's James R. Wilkins Campus in Winchester, Virginia, by speech pathologist, Julie Hunt. Ms. Hunt began using the technique after being introduced to the technique through one of Biklen's workshops in 1990.