SCOPE:

County Mental Health/Mental Retardation Administrators
Community Home Directors
Family Living Home Directors
Adult Training Facility Directors
Vocational Facility Directors
Early Intervention Program Directors
Non-State Operated Intermediate Care Facilities
   for the Mentally Retarded (ICF/MR) Directors
State Operated Intermediate Care Facilities
   for the Mentally Retarded (ICF/MR) Directors

PURPOSE:

The purpose of this Bulletin is to disseminate information on best practices with facilitated communication and guidelines for practice.

BACKGROUND:

The practice of facilitated communication has been growing in Pennsylvania since 1991. The Office of Mental Retardation issued Mental Retardation Bulletin No. 00-94-11, titled "Facilitated Communication" on March 1, 1994, providing a definition and basic information on facilitated communication. Speakers, facilitators, and others interested in facilitated communication have joined to form a State-wide Network that has offered opportunities to share experiences, information and training. The work of the State-wide Network has revealed the need for more current information on best practice in facilitated communication, as well as a set of guidelines. Attached to this Bulletin is a document titled "Implementation of Best Practice in Facilitated Communication Training...The Pennsylvania Perspective" that was developed by the State-wide Network.

Attachment

REFER COMMENTS AND QUESTIONS TO:
Ms. Carol Albert, Office of Mental Retardation, P.O. Box 2675, Harrisburg, PA. 17105
Phone: 717-783-5760
Implementation of Best Practice in Facilitated Communication Training...
The Pennsylvania Perspective

The Right to Communicate

"The right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate. In the name of fully realizing the guarantee of individual rights, we must ensure:
- that all people have a means of communication which allows their fullest participation in the wider world;
- that people can communicate using their chosen method; and
- that their communication is heeded by others.

Where people lack an adequate communication system, they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because they have been diagnosed as having a disability. Access to effective means of communication is necessary to exercise the constitutional right of free speech."

(Excerpted from Biklen, Borthwick, Shevin, 1992)

Facilitated Communication Training refers to the physical process of supporting the development of improved hand function over time, specifically, acquisition of a reliable selection response which ultimately can be used to independently access representational or written communication systems.

Facilitated Communication refers to the interactive and interdependent exchange in which a facilitator supports a speaker as a communicator. The speaker is engaged in the act of communicating while being facilitated or enabled to do so by another person.

Who might be a candidate? Candidates for facilitated communication typically are people who do not have an adequate communication system (full and rich expressive output) and/or who are experiencing difficulty in voluntary movement and control of their hands. Additionally, candidates are people who would benefit from enhanced communication options; complementing existing communication skills by broadening the expressive range.

Since 1991, people within Pennsylvania have been encouraged to approach the issue of Facilitated Communication Training from a collaborative model. The original formation of the Statewide Network was a multi-service system, family and consumer consortia with particular emphasis on setting long term goals for training, information dissemination and technical support. Out of this network has grown a quarterly newsletter and a system of connections which extends far beyond our state's borders with a membership of close to 2,000 people. The additional formation of a statewide subcommittee (as an outgrowth of the Pennsylvania Positive Approaches movement) has created a vehicle for continuous feedback and information sharing as people have become more involved in providing communication support to consumers across the Commonwealth. The subcommittee or roundtable provides an ongoing opportunity for people to gather at scheduled intervals throughout the year to address questions and concerns of implementation, training, ethics, to share information and experiences and to problem solve. It has been an effective tool for supporting local and regional networks and support groups with information and new ideas.
In addition to the Department of Public Welfare, Office of Mental Retardation, major advocacy groups in the state of Pennsylvania have committed their support to the issue of choice, options and control for people who experience communication difficulties. The Pennsylvania chapter of The Association for People with Severe Handicaps, The Association of Retarded Citizens of Pennsylvania, Pennsylvania Protection and Advocacy, Autism Support and Advocacy in Pennsylvania and the Developmental Disabilities Council of Pennsylvania have lent their voice to a position paper which identifies the following four basic rights or freedoms which are at stake for people with communication difficulties or differences:

- The Right to communicate and choose a preferred method of communication
- The Right to make choices affecting their lives - where to live, be educated, work and play
- The Right to privacy, dignity and respect and
- The Right to take risks.

Many persons wishing to explore FCT as a support are negotiating the current fallout of a popular press which has frequently focused on dramatic issues and ostensibly negative outcomes. As a result, barriers of fear and misinformation have been created. Subsequently, this option has been placed outside the reach of many persons who would like to try it and has disrupted services for others already receiving the support they need to communicate.

Early research, (Wheeler '93, Eberlin '93, Moore '93 etc.), from which many drew negative conclusions, has actually taught us a great deal about this new process. Discrepancies which appear to exist between experience and these research outcomes have triggered a world wide effort from researchers as they have sought to redesign their protocols to help us try to understand just why and how Facilitated Communication is working for people. While definitive answers are probably not going to be available for a few more years, newer research results are very promising. The most recent studies (Berger '94, Cardinal '94, Vasquez, '93 among others) point out just how fragile the FC exchange is and how delicate the instruments are that must be designed to capture it. As research proceeds it becomes increasingly clear that communication is a collaborative rather than a linear event and that the collection of data over time, in context (rather than in single sessions under artificial conditions) is critical. But the studies have validated the existence of the process and that has been an important step. In the meantime, as data is collected, there is a limbo to which people with communication disabilities are being relegated while anxious service providers, families, educators, friends, and advocates await the outcome of what has become a very public debate.

Many valid concerns have arisen: cost, time, training, validity, implementation, choice, and legality. All have become significant factors affecting a person’s options for using this method of communication. It is tempting to construct restrictive parameters or guidelines which would eliminate or reduce the possibilities of any negative experience as we, practitioners and family members, attempt to support people with disabilities in a new way. However, Pennsylvania has the resources and the ideological base to be able to produce positive, supportive considerations which reflect best practice in facilitated communication and human service provision, allowing everyone in this partnership to feel comfortable during a unique and challenging period of time.
Promising and Best Practice

Facilitated Communication Training is currently considered a promising practice in supporting people to express themselves. As with any supportive option, competent implementation is essential in order to achieve meaningful outcomes for all involved in the process of facilitation.

Over the past two years much furor has arisen within the professional community concerning an empirical data base. This has been especially noteworthy in instances where individuals who were thought to have "severe" disabilities have demonstrated unexpected levels of thought and literacy. While reports from studies examining facilitation have shown mixed results, the focus on an empirical data base appears to be inhibiting people from exploring Facilitated Communication Training on a case by case basis.

With this information as a backdrop, it appears worthwhile to briefly differentiate "promising" from "best" practice. The primary difference between a promising and best practice is the establishment of a comprehensive, longitudinal data base established through published research. As such, all best practices begin their life as promising practices and over time become accepted as best practice through published research. While there is an acknowledged controversy among members within the professional community concerning the existent data base on facilitation, there continues to be a growing number of success stories of its viability from families and professionals across the nation (inclusive of Pennsylvania). Additionally, several reports have appeared of people reaching independent levels of communicating. These reports, combined with a promising and growing body of initial research results, would suggest a typical evolution or development of this promising practice toward a best practice.

Based on this rationale, Facilitated Communication Training should continue to be explored...and most certainly not withheld or withdrawn based on the desire for a longitudinal data base. This is not to suggest that establishing such a data base is not important...it most certainly is. The important point to understand is that like any validated best practice it will take time for such a data base to evolve.

What is Current Best Practice?

Based on our knowledge, at this point in time, best practice in Facilitated Communication entails thoughtful implementation of the following components:

EMPLOY A COLLABORATIVE TEAM APPROACH. All significant people with whom the prospective communicator is involved (family, friends, support staff, connected professionals, etc.) should be aware of and have the opportunity to discuss Facilitated Communication Training as an option of support in a person's life.

ASK THE PERSON IF IT MAKES SENSE TO THEM AND IF THEY WANT TO TRY USING FACILITATION. (Have an experienced facilitator support their initial responding and participation.) The person who is the communicator needs to be part of the team from the onset and at the same time the focus of the team. For some people, trying this new method of support for their communication is both a frightening and exciting prospect and they need to know and be assured that important people will be around to provide needed support and that those people are going to stay the course with them.
ACHIEVE CONSENSUS IF NOT TOTAL AGREEMENT. Facilitated Communication Training may be a challenging concept for some of the team members to support but the need to acknowledge people's fears and concerns up front is essential if long term commitment is to be achieved. Once the team can at least agree to try introducing and supporting facilitation then providing adequate information and training to all concerned is the next step.

PROVIDE TRAINING AND LAY THE GROUNDWORK WITH STAFF, FAMILY, ETC. People need adequate information and skill development to feel confident enough to proceed effectively with the potential communicator. Ideally, as the team is receiving training, the experienced trainer/facilitator will be simultaneously working with the speaker to begin the process of discovering support levels, position, appropriate aides/device, and any other significant information which will ease the transfer to others on the team as soon as possible...during the first session if feasible. This achieves one of the most important goals of Facilitated Communication Training and that is to:

PROVIDE MULTIPLE FACILITATORS IN ALL ENVIRONMENTS. In order for skills and confidence to develop, the team must be extensive enough to provide communication access throughout the day and across all environments. An ideal example for a school age speaker might be to have as facilitators; parents, siblings and other important family members, and teachers, aides and/or peers in the school environment. An adult example for someone in a group home might include: at least one staff person on each shift, family members, a friend, co-workers and perhaps a counselor. Bringing as many people as possible into the process insures access to communication options and partners and affords the person with a communication impairment the same opportunity as the rest of us for meeting people and making friends. We have a large pool of prospective people from which we ultimately find the few individuals with whom we are truly close in life. People with disabilities have historically had limited options for meeting large numbers of people. This natural selection process works to the extent that we create the opportunities for people to form relationships.

CONSIDER TECHNOLOGY OPTIONS TO ENHANCE A PERSON'S ABILITY TO COMMUNICATE. The team and the speaker should explore the possibilities that are available in the field of technology applications. Individually assess specific technology options based on feedback received from the speaker. While technology is not absolutely essential to this process, it can circumvent many physical, visual and movement difficulties a person may have, thus allowing them to achieve more independent levels of communication. Some people prefer not to use technology. Always have the speaker assume the lead on this issue.

**Important Technical Support Skills**

GET AND GIVE CONSTANT FEEDBACK. Keep checking with the person if you are giving the right physical support, if you understand them correctly, if they want to stop or continue. Provide ongoing suggestions to them about their skill development, always supporting the evolution toward independence. Be observant of their visual attention to the communication surface, offering frequent encouragement to keep focused. Let them know when you don't understand and support them to clarify their messages.

PROVIDE ADEQUATE RESISTANCE AND CONSISTENT PULL BACK. The pressure exerted should be adequate to ensure a smooth, rhythmic hand and arm movement without being overpowering. It is a delicate balance. Pulling the hand back after each selection will help to establish the rhythm which is essential in training a motor response. Matching
your support to the person's skill level ensures consistent improvement in their ability to move to more independent levels.

**WORK TOWARD INDEPENDENCE RIGHT FROM THE BEGINNING.** This is something that must be explained to each person in the first session. Free and full expression is the communication goal for each of us and we offer the support of facilitated communication training to a person with the hope and understanding that they too will achieve that goal. At the same time it needs to be clear to the team that not all people will be able to reach independence but still need the opportunity to communicate. This is a goal that is worked on collaboratively with the speaker at a rate with which the speaker feels comfortable.

**KEEP GOOD RECORDS.** The team should work with the speaker in compiling an ongoing journal or portfolio. The information in the portfolio could include but is by no means limited to:

**Examples of content:**
- favorite topics
- unique spellings
- unique word formations
- unusual manner of expression

**A record of information not known to the facilitator**

**A description of observable circumstances:**
- physical supports needed
- individual rhythms and pacing
- movement problems
- behavior which reflects the typing

**A description of speech patterns which accompany facilitation:**
- words that correlate with typing
- words said before or after typing
- letter names that correlate with typing
- letter names said before or after typing
- unrelated verbalization

Information selected for the portfolio would be subject to the approval of the speaker. It must be remembered that the output belongs to the person who has typed it and as such must be dealt with confidentially.

**IDENTIFY A MANAGER OR COORDINATOR OF INFORMATION.** Someone on the team, (it can be a family member, main facilitator, or anyone willing) needs to assume the responsibility of assisting the speaker to accumulate ongoing information and in turn, inform other team members of gains, difficulties and problems solved. Their main function is to keep the portfolio and the team members current and relevant.

**FOLLOW UP WITH TECHNICAL ASSISTANCE TO STAFF AND FAMILIES.** A once-and-done in service will not provide a team with adequate support to weather the ups and downs of the early days and weeks of assisting a speaker to get started. Nor will it prepare the team to adequately address many of the issues that evolve when someone begins to communicate. It is essential to have the original trainer or other experienced person available to the team on a regular basis to answer questions, assist in problem solving and be a resource for such things as technology applications, generalization issues, and on-going monitoring and support of skill development in new facilitators.
APPRECIATE THAT THIS IS A PROCESS TO TRAIN A NEUROMOTOR SYSTEM AND THAT IT TAKES TIME. If we think of any of the physical skills we have acquired we realize that it takes time; for example, tennis lessons, driving a car, ice skating. People who are candidates for facilitated communication training have significant difficulty acquiring physical skills (that's why most of them have trouble speaking) and so they need more practice and time to acquire even simple motions that are reliable for them. Recognize that an enormous amount of effort is being exerted by the speaker in the process of making intentional selections from a keyboard or symbol board and coordinating their visual focusing at the same time. Patience is essential if we are to persist while a person acquires those skills. Initially, many people complain of fatigue after brief intervals and only slowly build their tolerance for longer sessions. Many are not sure that they can do this and will only believe it themselves after a considerable number of successes and a lot of support.

CLARIFY MESSAGES. Be thorough and clear in determining exactly what the intent of the person was when they shared their information.

- Unusual speech patterns that have been noted in some people with autism and other related disabilities may also appear in the written communication. Non-verbal people may also show unusual patterns in their written communications. For example, messages may have pronoun reversals, unusual grammatical sequences, omissions and substitutions of key words and/or connecting words
- Learning styles and expressive styles are different for all of us.
- Don't assume you 'know' what other people mean!
- Realize that all people will not type but some will be able to use symbols, pictures, phrases, whole words or combinations thereof. As such, facilitators need to be careful to verify the speakers selections and openly discuss the possibility that the facilitator can make mistakes and misinterpret the speaker's meaning. Speakers must be made to feel comfortable telling the facilitator, in some way, when they are incorrect. Most communication pairs develop a signal that conveys that message in a timely fashion.
- Be aware of the power that written communication has and the weight it tends to carry. The same thing said through writing is more powerful than the same thing delivered through speech. Guard against the tendency to:
  - over interpret
  - give undue importance to written communication.

BE AWARE OF THE POSSIBILITY OF FACILITATOR INFLUENCE. From the earliest accounts of facilitation there have been cautions raised about facilitators influencing the communication of speakers. However, this is reducing the issue to a very linear process. Certainly facilitators can and do anticipate responses of the person whom they are supporting. But speakers also seek subtle signs from the facilitator in an ongoing fashion. Therefore it is extremely important that facilitators continually monitor their own performance in terms of cueing. Cues can be:

(1) Physical in nature (subtle pressures and movements applied to the speakers' movement)
(2) Anticipatory in nature (jumping ahead of the speakers performance) This can take the form of predicting:

Speaking aloud, as in anticipating letter or word completion before the speaker makes the selection:

Forming the word silently (mouthing) which can easily be detected.

Mentally assuming what the person is about to select. The facilitator can easily envision a letter, word or symbol in error and actually tell the speaker they have made a wrong selection when the speakers intent may have been correctly executed. An example of that is when a speaker might type **VER** and then the facilitator imagines **Y** to complete the word. However, the speaker may have another word in mind (**VERTIGO** for example) and may attempt to select the correct letters. The facilitator may verbally correct the speaker, pull back, tell them to try again when the speaker does not select the **Y** to complete the word which the facilitator has anticipated. Instant influence!

(3) Reactionary in nature - facial or non verbal signals (for example, body shifts, sighs, tensing) which might cue the speaker that a pending selection is not satisfactory.

The most desirable habit to cultivate is to focus on the physical presence of the speaker and their movement (physically listen). Empty your mind or think of something neutral and monitor the feedback you give to speakers in an ongoing fashion. In this manner you will focus on the area with which speakers need assistance, which is the physical realm and you will avoid focusing on the development of the message while it is being produced. Clarifying can come AFTER the speaker completes the sequence of letters. Just as our questioning can take speakers in unintended directions so too, can our anticipation of letter selections influence the speakers output.

**PROVIDE OPPORTUNITIES FOR REAL CHOICE.** Brainstorming with the team to determine where choices are available for children and adults and how those options might be expanded is an essential ingredient to providing meaningful opportunities for real communication in a person’s life. Initial identification of those options must be followed by serious and thoughtful consideration by the team on how best to support the person in their choice making. The important issue is that there need to be outcomes for people now that they have a voice. The whole point of communication is to gain control in our lives and over our destinies. We can support people to develop a communication system but then we must listen and consider what they are saying. Concurrently, the person may need support from the team to learn how to compromise when requests are unrealistic or require long range planning, for example, a big vacation or an expensive purchase. A good benchmark to use would be to consider what is reasonably, possible for anyone in that age bracket, financial circumstance, state of health, etc.

**REMEMBER THAT FACILITATION IS ONE OF MANY SUPPORTS WHICH AN INDIVIDUAL MAY CHOOSE IN THEIR LIFE TO PRODUCE EFFECTIVE COMMUNICATION.** The goal is to communicate and all people communicate in a variety of ways. The rule should be "whatever works" to achieve the richest and fullest expression possible.

**STAY CURRENT.** Keep up with developments in the field. It is a rapidly evolving and expanding body of information. Keeping current is absolutely essential. If the team does not keep up it is at risk of distorting or perverting this process of support. Do stay connected with the Statewide Network and be proactive in forming local support groups which can expand the team’s ability to provide tailored supports and to problem solve. Exploring the concept of personal support circles will enhance access to consistent, sustained communication opportunities for the speaker.
SUPPORT SPEAKERS WITH VALIDATION ISSUES. At some point, some people may need to formally validate their communication in some way. The portfolio approach and multiple facilitators should suffice and will, over time, validate the person's output to everyone's satisfaction. Naturalistic methods are preferable to intrusive, "testing" situations. Observations of major behavioral changes, movement to independent skill levels, etc. are all important validations that Facilitated Communication Training is having an impact on a person's life. However, when confronted with legal issues or major life decisions it sometimes becomes necessary for the speaker to demonstrate the validity of their communication to others outside the team.

(1) Validation of information generated by any speaker can be confirmed through the use of a second, naive facilitator. Give speakers opportunities to work with multiple facilitators and message passing tasks on a regular basis under typical circumstances, i.e., students reporting weekend activities to classroom staff and vice versa or people relating events or telling jokes, etc. to facilitators on different shifts. This will help build confidence and skill should the need arise. (For proceeding in a more formal manner with validation refer to the attached guidelines for dealing with sensitive information.)

(2) In cases of legal allegations, courts of law are increasingly requiring that people using facilitated communication demonstrate authorship during court proceedings. This is a highly stressful set of conditions under which to "perform." It can mean that the speaker must demonstrate message passing skills or it can mean that the speaker will be required to type the allegation or answer questions independently. If these conditions are imposed on a speaker it is essential that the counsel for the speaker negotiate with the court a period of grace or practice time for the speaker (1-3 months) and "reasonable" as opposed to "impossible" conditions of performance. This gives the speaker an opportunity to familiarize themselves with the circumstances which will be required of them in the courtroom.

Final Thoughts

Above all it is important to remember that Facilitated Communication Training is a support which we offer to people to enable them to be more effective in their communication efforts. It evolves from a perspective that assumes that all people have a desire, a need, a right and the competence to communicate. It also assumes that any person should have the right to select the approach(es) that works best for them. Additionally it assumes that the person who knows and understands what is needed is the person who is requiring support in communicating.

For Further information contact:

Facilitation Supports, Inc. • 717-275-5361
Bibliography


