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**UPFRONT**

In case you haven’t noticed (and I’ll bet you have), there is a brouhaha going on about Facilitated Communication, known in many places as FC. For a myriad of reasons, I have avoided entering the public discussions of FC until now. It was persistent, gentle prodding from some close colleagues and the following quote from my local paper that led me to do this issue: “Criticism is something you can avoid by saying nothing, doing nothing and being nothing."

_Criticism is something you can avoid by saying nothing, doing nothing and being nothing._

*Gem of the Day, Monterey Herald*

Let me be up-front. I deplore the battlefields surrounding the FC phenomena. People with disabilities and their families need help sifting through this quagmire. Emotionalism seems to have captured professionalism and held hostage good, well-intentioned people. This issue considers what is currently known about FC training within a context of clinical practices in AAC. (cont. page 2)

People do not define FC the same way. Nor does the literature. In fact the definition seems to be evolving, even within individuals. As luck would have it, Crossley and others just happened to be working on definitions, which she graciously shared:

In facilitated communication a partner (called a facilitator) enables a person with a severe communication impairment to achieve the movements necessary to make selections from items such as objects, pictures, purpose-made symbols, written words or letters for the purpose of communication. Typically the facilitation user needs help in achieving functional hand use. The amount and nature of the facilitation provided varies depending on the requirements of the task and the needs of the individual. A facilitator may be a therapist, teacher, caregiver, aide or friend—anyone who has learned the specific skills involved in facilitating the choice-making of one or more individuals.

Facilitated communication training has been used with children and adults with developmental disabilities (e.g., autism, mental retardation, cerebral palsy, Downs syndrome). However, characteristics of people who can benefit from facilitation are not well delineated.

The nature of support provided during facilitation includes:

- **Physical support** - A facilitator holds/touches the hand, wrist, elbow, or shoulder of someone who has difficulty pointing to an alphabet board or communication display with pictures, or typing on a keyboard. The nature of the support often involves the facilitator exerting backward pressure between selections.
- **Emotional support** - The facilitator has high expectations (cont. page 2)
Augmentative Communication News

For Consumers (cont. from page 1)

First, some personal history. I initially learned about FC during a trip to New Zealand and Australia in 1989. On the face of it, professionals with positive attitudes were prompting people with disabilities to point to a display or a keyboard. Frankly, I was surprised to learn that accusations of sexual abuse made during facilitated communications were subsequently shown to have been authored by the facilitator.

An alarm sounded from Down Under, alerting us all to the perceived benefits, and the potential costs and risks involved in using FC. Unfortunately, when FC was introduced on the east coast of the United States in 1990, the issue of authorship (and therefore the validity of the technique) still had not been addressed. Within a year, the mass media announced on television that FC was a breakthrough for people with autism. I can recall thinking as I watched, "Oh no, here we go!" Then, I turned off the TV and went back to my life. Luckily, not everyone did. I would personally and publicly like to thank those colleagues who pursued the knowledge that we have needed to guide us.

In preparing this issue, I read three excellent books by persons with autism: Emergence Labeled Autistic1 by Graddin and Scarian and Nobody Nowhere2 and Somebody Somewhere3 by Williams. I read Martin's Out of Silence,4 a well-written and thoughtful book about the nature of autism and a family's journey. I studied Crossley's 1994 book Facilitated Communication Training5 and the informative book Facilitated Communication: The Clinical and Social Phenomena6 edited by Shane. Many articles, audio tapes, videotapes and interviews later, I started writing. These pages are the result. For Consumers considers the unfulfilled promise of FC. Governmental gives reactions to FC from U.S. agencies and organizations. Clinical News addresses issues relevant to the relationship between FC and AAC. University/Research and Equipment look to the future.

The words are mine, but my thanks go to those who shared their opinions, research, experiences, thoughts and observations. They are listed as Resources along with Selected References on page 8. For a complete list of more than 60 references I used, please send a self-addressed, stamped envelope to 1 Surf Way, #215, Monterey, CA 93940.

Augmentative Communication, Inc. announces

ALLIANCE '95
Outcomes in AAC
February 19 - 22

This first-of-a-kind conference welcomes the AAC community to Asilomar Beach in beautiful Monterey—just 5 minutes from the Pacific Ocean. Registration is limited. If you want me to save a place for you, please fill out and return the enclosed flyer as soon as possible.

Sarah W. Blackstone, Ph.D.
cultural data are an important component of best practices.

At this writing, nearly 400 people with disabilities (mostly autism, pervasive developmental disabilities and/or mental retardation) have participated in more than 40 controlled studies designed to determine authorship. In most studies, participants were familiar partners and facilitators were "skilled." Everyone was informed about the nature of study and had consented to participate. Results of published studies that have controlled for facilitator knowledge are consistent and clear:

- People being facilitated rarely typed relevant, accurate messages.
- When accurate messages were typed, content was not sophisticated and did not reveal unsuspected literacy skills.
- When double-blind procedures were used, results showed facilitators were authoring messages they attributed to the person they were facilitating.
- Facilitators were not aware they were influencing the content of the person's message.

While descriptions of successful facilitation continue to be presented at conferences and in some publications, the overwhelming empirical evidence has led organizations and agencies to conclude there is insufficient basis for FC (see Governmental). Clinicians, educators and family members are proceeding cautiously, as well.

Descriptions and testimonials can not be the foundation of our knowledge base. Neither can they be ignored.

**Explanations**

These studies have raised many questions. Why are people unable to communicate messages when facilitators don't know the intended message? The obvious explanation is that facilitators are unknowingly controlling message content. However, other explanations have been offered:

- **FC can not be tested.** This clearly is not the case. Dyads (facilitator and person being facilitated) in study after study were reported to be cooperative and enjoyed participating. The problem isn't that FC can't be tested. The problem is dyads don't pass the test items unless facilitators know the answers.
- **Unconscious facilitator control is less likely to occur in natural settings.** Under the circumstances this explanation seems highly unlikely. In any case, it must be demonstrated, as well as described.
- **Facilitator influence is not a problem because all communication is collaborative.** True, communication is a collaborative process, particularly when one partner has a severe communication problem. However, the fact that we are subtly influenced by our partners does not make us unable to communicate things we know but our partners do not (double-blind studies). Nor does it make us able to communicate things only our partners know (single-blind studies). Physical control is not the same as subtle psychological, sociological or cultural influence. Physically directing a person (even unwittingly) removes a person's right to choose. It is a potential infringement of a person's right to say and be who she is.
- **Some persons with disabilities are telepathic.** The logic goes like this: When it appears that a facilitator is typing the message, it means the person with a disability is reading the facilitator's mind and typing what the facilitator is thinking/seeing. Maybe? Maybe not. What we personally believe about telepathy is irrelevant. As a professional, I certainly wouldn't walk this one down the aisle without first checking my license at the door.
- **How are facilitators unconsciously influencing typing?** The following phenomena may account for facilitator influence. While there is no direct evidence of either, neither explanation has been eliminated at this time.

- **Clever Hans.** This phenomena was described in the early 1900s. It refers to the ability of one person to influence another's behavior using subtle, conditioned cues that are not necessarily conscious. Hans was a horse who seemed to answer complicated questions, but actually had learned to follow his trainer's cues.
- **Automatic writing.** Documented for over 40 years, this phenomena occurs when people (often in a relaxed state or under hypnosis) are paying attention to something else while writing. Characteristics of automatic writing samples include:
  - content reportedly unknown to the writer or forgotten by the writer.
  - unusual spellings, word choices and grammatical structures.
  - writing that is more or less sophisticated than the person's usual work.
  - surprising metaphorical, erotic or poetic content.

**What's to be done?**

The validity and the reliability of using facilitation as a means of accessing previously unknown intelligence and literacy skills for a large number of persons with autism and other developmental disabilities have not been shown. More importantly, people have been harmed. Table I on page 4 outlines five important areas for consumers (and professionals) to consider before "giving it a try":

- informed consent, appropriate team assessments, adequate facilitator training, ongoing review of information, and the use of validation techniques.

Some components of FC training, while not unique, are based on well-established clinical practices (e.g., physical prompts systematically faded, positive reinforcement, emotional support, positive expectations, respectful treatment and environmentally-based training). Even so, people and institutions charged with protecting people with disabilities now have no alternative but to consider FC an experimental procedure.
**Augmentative Communication News**

### Table 1. Ways for consumers to avoid problems with facilitated communication

| Informed Consent | Get informed consent statements from facilitators. Give your informed consent. These statements should include: 1) The technique to be used is controversial. 2) Thoughts and ideas that may be taken to be those of a person being facilitated and that may be acted on as if they were his or hers, may, in fact, be the thoughts and ideas of a facilitator. 3) There have been reports of a number of sex abuse allegations made through facilitated communication, which were subsequently shown to have been made by the facilitator, not the person being facilitated. Such an allegation must be considered a statistically small, but known risk of the use of facilitated communication.
| Assessment | Use FC training only after an AAC assessment. Consider other options for accessing communication displays.
| Training | Make sure all facilitators are adequately trained and supervised.
| Validation Procedures | Be certain about who is authoring the messages generated. Make adjustments, as necessary. See Clinical News.
| Balanced Information | Don't treat FC as a cause to be won or lost. Surround yourself with those who take a balanced view and read publications.

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### Governmental FC Policy statements

**Consumer protection laws, codes of ethics and policy statements are being invoked to remind professionals and institutions of their responsibilities and to protect persons with disabilities and their families or guardians. Sample segments of recent position statements on FC in the U.S. follow.**

**Note:** These agencies periodically review their policies to accommodate new findings.

**American Association of Mental Retardation**


"A substantial number of clinical evaluations and well-controlled studies indicate that Facilitated Communication, a technique of physically assisting people with autism or mental retardation to communicate through typing or communication boards, has not been shown to result in valid messages from the person being facilitated. Therefore, be it resolved that the Board of Directors of the American Association on Mental Retardation does not support the use of this technique as the basis for making any important decisions relevant to the individual being facilitated without clear, objective evidence as to the authorship of such messages."

**State of Massachusetts**

A cautionary statement to all persons under its jurisdiction from the Executive Office of Health and Human Services: Department of Mental Retardation, October, 1993.

"It is the policy of the Department to take no final official action as a result of a facilitated communication, unless the communication can be supported by other statements or evidence."

**State of New Hampshire**


In the last six months, research has demonstrated a significant lack of clinical support for FC. The likelihood of facilitator influence is well documented. These factors have led us to change our position regarding provision of FC services. At the present time, we feel that we must exercise greater caution and consequently will not provide FC evaluation, consultation or training. There are many unanswered questions around FC. NHATEC will continue to monitor the research.

**State of New York**


"In conclusion, the unsupervised use of FC for persons with severe communication impairments can lead to serious, if unintended, negative consequences for the individual, family members, staff, and program administrators. The importance of these negative outcomes is heightened by scientific research reports that cast doubt on the authenticity of FC, and suggest that facilitators may often unwittingly be the source of the typing. This Advisory to the Field is intended to inform interested parties about the significant..."
issues related to FC and to recommend procedures that should be in place to verify the validity of any facilitated communications in sensitive areas or that deal with significant life decisions. It is vital for consumers, family members, legal guardians, facilitators, professionals, and program administrators to be aware of the controversial nature of FC and become familiar with relevant research findings reported thus far. The following Guidelines for FC Training are provided as a model for general use. . . . The adoption of . . . any of the recommendations contained in the Advisory, is not mandatory."

American Academy of Child and Adolescent Psychiatry

"Facilitated communication (FC) is a process by which a facilitator supports the hand or arm of a communicatively impaired individual while using a keyboard or typing device. It has been claimed that this process enables persons with autism or mental retardation to communicate. Studies have repeatedly demonstrated that FC is not a scientifically valid technique for individuals with autism or mental retardation. In particular, information obtained via FC should not be used to confirm or deny allegations of abuse or to make diagnostic or treatment decisions."

Final comments
Professional organizations support treatments deemed valid, reliable and acceptable within an area of practice. Four years after the introduction of FC in the U.S., three key organizations still remain silent: American Speech-Language-Hearing Association (ASHA), American Occupational Therapy Association (AOTA), and the U.S. Chapter of the Society for Augmentative & Alternative Communication (USSAAC). Their lack of guidance is not helpful to consumers or to professionals.

Clinical News
Read more — Discover less!

I was surprised to discover that some people perceive AAC and FC as synonymous terms. They are not. FC is a technique for accessing communication. AAC is an area of practice that offers a wide range of strategies, techniques, tools and technologies to enhance communication. AAC requires the involvement of multiple disciplines working as a team. The field of AAC exists because:

- a substantial number of people in the world have difficulty speaking and/or writing and therefore communicating.
- participants in AAC share certain principles and beliefs, i.e., communication is the essence of life.
- communication is a basic human right.
- communication is both an end in itself and a means to other ends such as choice, independence, education, employment and membership in one's own community.

Some people perceive AAC and FC as synonymous terms. They are not.

- instructional tools, techniques and strategies and an increasing array of assistive technologies (both low and high-tech) are available to help people who don't speak participate in their communities and communicate their thoughts, ideas and desires.
- research, educational programs, materials and technologies support the ongoing development of the field.
- health-care and educational systems recognize expertise in the area of AAC and fund research, development and the delivery of clinical services for people with severe communication problems.

What is the relationship between AAC and FC? Some say there is none because FC is not valid. However, most would agree that assisted pointing to a communica-

1. The communication process. Communication defines a series of relational events. In the early 1980s, results of interaction studies in AAC demonstrated that speaking partners dominated conversations with AAC users and affected their interaction style and message content. Specifically, speaking partners:
- asked a large number of yes/no questions (many of which they knew the answer to),
- interrupted,
- disregarded communication acts expressed through nonverbal means when communication displays/devices were present, and
- took more than their share of conversational turns.

AAC users, on the other hand, were passive and rarely initiated conversation or introduced new topics.

As a result, clinicians recognized the need to instruct and support the partners of AAC users (facilitators), as well as the AAC users. Clinicians began to teach strategies to confirm (or correct) a partner's interpretation or translation and to repair communication break-
Augmentative
Communication
News

Clinical News continued from page 5.

Table II Ways to Monitor the Exchange of Information during Facilitated Interactions (Single Blind Procedures)

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<th>Activities should be fun and non-threatening. Participants attention, expressive capacity and motivation should be monitored.</th>
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<td>1. Every week, ask the person about something you don't know. Keep a log. Corroborate all responses. You can use an event description: “What did you do this weekend?”</td>
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<td>2. Using familiar educational materials (e.g., objects person uses/communication cards). Ask person to tell you or point to word/picture. Make sure facilitator can’t see materials.</td>
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<tr>
<td>3. Ask the facilitator to leave and go several rooms away. Then tell, show and do something with the person.</td>
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<tr>
<td>4. Person does an activity lasting 10 minutes (e.g., make a snack). Videotape the sequence. The facilitator returns asking “What happened?” Facts are written down and checked against the video.</td>
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<tr>
<td>5. Person plays with an object and sees word for the object which is put up on a board next to other words. Object is put away in a box. Facilitator returns and asks person to describe the object.</td>
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<td>6. Cartoon Quiz: Child watches a cartoon while facilitator is not present. Someone inquires child pays attention and comments on items that will be asked later. Facilitator returns and facilitates a child to answer a multiple-choice quiz about the cartoon. Questions are presented in written or in oral form. When success is achieved using multiple choice format, children who spell are asked to type.</td>
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downs. They coached AAC users until they began to exert control and assume an active role in the communication process.

Of course, communication control issues in FC extend well beyond concerns raised by AAC interaction studies. Yet difficulties identified a decade ago are manifest in the communicative patterns of dyads using FC. Table II lists six ways for clinicians to monitor facilitator influence. Other resources are also available (see the Governmental section and the chapter by Shane⁷). Procedures are single-blind. This means the facilitator does not have access to information the user is being asked to express.

Access techniques. Best practices in AAC require that occupational (OTs) and physiotherapists (PTs), not educators or speech-language pathologists, guide decisions being made about motor skills (i.e., capabilities, positioning, seating, access methods and instructional strategies). The role of the OT and PT is critical and defined in the AAC literature, but often not presumed in FC. Questions requiring OT input include:

- Are there technologies that can help people learn to point more efficiently and effectively?

Modes of communication. People with severe disabilities often communicate their intent using multiple modes of expression. On occasion, it has been suggested that facilitators should ignore or inhibit the use of speech and “natural” gestures during facilitated typing. For several reasons many do not agree:

- We know “challenging” behaviors express communicative intent. It is important to recognize the meaning and function of these behaviors. In fact, when professionals, family members, and friends recognize “signals” as meaningful and legitimate expressions of a person’s state, opinions, desires and needs, their behaviors often improve.¹⁸
- Communication aids and devices can make extraordinary differences in people’s lives. However, even “expert” users of low and high tech devices often rely on natural gestures, body language and speech to relate to the people closest to them. When socially acceptable forms of communication are available (and preferred by a communicator), it is naive to insist someone use a device or point to a display.
- Speech is always desirable. People with severe communication impairments should be encouraged to talk. Echolalia, seems to play an important function in language development, especially for children with autism.¹⁹ It should not be dismissed.

Communicative competence. A model of communicative competence in AAC includes, operational, strategic, linguistic and social competence.²¹ The dictionary defines competence as “having sufficient means for one’s needs.” Competency exists on a continuum. It is a relative, not an absolute term—relative both to the individual and to specific areas of competence.

Personally, I resent any implication that treating someone as competent means you expect her or him to be bright and linguistically able. Many, many people who use AAC techniques are persons with mental retarded who are not literate, at least not yet. Many communicate very well, and it would appear, sufficiently to meet their needs. They are “competent” communicators.

Facilitator training. Initial FC training workshops in the U.S. consisted of one to two days of lectures, videotapes, and limited practice with other able-bodied participants. Two years later, more than 800 people from the U.S. and Canada were trained as facilitators. These people trained others, who trained others. While enthusiasm was passing on, skills were not. This scenario should not be repeated.

Some attribute today’s FC problems to insufficient training.²² Crossley, for one, says that not a few days, but 80 hours of classroom combined with guided practice over a six month period may be necessary for those who wish to facilitate more than one person (without supervision) or teach others how to do it. She feels it is important that facilitators understand how FC fits within a broader AAC framework and know how to validate on a regular basis.


Some in the AAC community feel it is premature and irresponsible to spend more time and money studying FC. Others feel important, unanswered questions remain with many extending beyond the issue of authorship. For example:

- **Type 1 and Type 2 FC.** Are there Type 1 and Type 2 FC communicators? Rimland writes, “The discrepancies between the high-level communication skills reported by Biklen and Crossley, compared with the levels reported by Cardinal, Berger and others is remarkable. Perhaps there are two different FC phenomena: Type 1 consists of simple one- or two-word responses, usually accomplished only after a good deal of training and experience. Type II manifests quickly, in the absence of meticulous training in reading. Messages are often profound, insightful and witty.” He points out that of the 400 subjects who have participated in 44 controlled trials of FC only about 50 showed any ability to “facilitate.” In every case, Type I rather than Type II FC was observed.

One way to demonstrate Type II FC would be to carefully document just one extraordinary case.

- **Independence.** What is the road to independence in FC? Reports that individuals who were facilitated are now communicating independently call for careful investigation so that the process is understood. Of course, documentation of a person’s skills/abilities prior to the introduction of FC is critical if changes are to be attributed to the use of FC. Longitudinal studies (both quantitative and qualitative) would be particularly helpful.

- **Facilitators.** The biggest challenge ahead may be sorting out issues related to facilitators. What is going on? How can people be unaware of their influence in study after study (double-blind)? Is this phenomena observable in other clinical arenas? If so, how, where and under what circumstances?

The Methods

Qualitative and quantitative research contribute to our understanding of human communication, its disorders and effective treatments. Arguments that one research methodology is “bad” and another “good” seem especially unproductive when so many questions about FC remain unanswered. Any research study should be designed and carried out carefully. This is true of clinical practice, as well. To date, quantitative research designs have been closely scrutinized. It is time also to hold qualitative researchers to the same standards. For example, a few researchers in AAC have conducted ethnographic studies and adhered to strict methodological standards, which include: emic (insider) and etic (outsider) descriptions and a cyclical collection and comparison of data, as described:

- Emic description: Descriptions of socially, linguistically and culturally meaningful behavior from the perspective of the participants (individuals within the group.) Includes formal and informal interviews. Takes into account the opinions, views, feelings and interpretations of those with first-hand involvement.

- Epic description: Descriptions from outside the participants' perspectives. Transcripts and videotapes of interactions may be used.

- Eyeclical collection and analysis: Continual attempt to define and redefine appropriate research questions. Recurrent collection and analysis of data.

- Comparison of data: Researchers compare what is observed in one situation to similar situations within and across groups.

Equipment

Beyond the typewriter

More than 100 AAC devices are available today for people who have difficulty speaking or writing. Features include different ways of accessing the device, different language capabilities, enhancement features and a variety of output options like speech, printers and color displays.

Please note: When a double blind procedure is used, it is necessary to get informed consent from the facilitator, to give quick feedback and to offer external counselling services. The reaction by and impact on someone who is dedicated to the person and the FC procedure and is paid to be a facilitator can be devastating when results show messages are authored by the facilitator.

- **Supports.** What is the value of using physical support? Why does FC seem to improve attending behaviors? Do we move too quickly to technological solutions? Should we do more hands-on, i.e., touching people more?

- **Outcomes.** What happens to individuals who have been trained as facilitators? What happens to those who are facilitated?
References

For a complete list of references, please send a stamp self-addressed envelope to 1 Surf Way, #215, Monterey, CA 93940.


7 Rosemary Crossley. Personal communication (July, 1994).


14 Howard Shane. Personal communication (July, 1994).


16 Robert Horner. Personal communication (July, 1994).


21 Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. AAC, 5:2, 137-144.


23 Rimland, B. (1994). Editor's comments. Autism research review international. 8:2, 2.


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