

The following two articles plus interspersed shorter notes explore the burgeoning controversy over Facilitated Communication, a well-meant but much misused and misinterpreted technique intended to help autistic and other impaired persons to communicate.—Editor

Anguished Silence and Helping Hands: Autism and Facilitated Communication

JAMES A. MULICK, JOHN W. JACOBSON,
and FRANK H. KOBE

The vulnerability of parents of handicapped children to offers of easy or miraculous cures is legendary among health professionals. Like most legends, this one has some truth to it. Parents are, in fact, astute critics of the professionals who work with their children. They react strongly to signs of professional aloofness or apparent disinterest or dislike and become understandably fearful at signs of indecision. They want intensely for their children to overcome the handicap, to grow out of it, to get some swift and effective treatment. They can forgive and forget aloofness or vague reasoning as long as help and hope are forthcoming. This transformation of distrust into trust can happen in the space of a single breath.

This is not abnormal. All parents want the little boy or girl they see before them to have a world full of promise and happiness, to grow into the kind of adult they can so vividly and lovingly imagine. Indeed, they begin nurturing dreams of the person their child will become from the time of their first knowledge of conception. Imagined details change with the passage of time and as experiences unfold, especially for parents of handicapped children as facts



Acceptance of a new procedure being used to reach developmentally disabled children is based on the emotional appeal of dramatic or easy cures, questionable science, and possible perceptual bias. Its claims cannot be independently scientifically verified.

about the handicap and resulting limitations become evident; but hope, like the child, is seldom abandoned. It keeps people going.

Parents of handicapped children spend much time visiting and listening to a bewildering variety of professional people who sometimes present conflicting information. Despite literature designed to improve parent-professional collaboration (Mulick and Pueschel 1983; Pueschel, Bernier, and Weidenman 1988), misunderstanding is commonplace, and ever-present stress increases miscommunication. Stress affects both parent and professional. Nothing can lessen the emotional shock for the parents who hear that their child has a significant disability likely to result in lifelong limitations. The anguish is profound and tends to be rekindled by everyday events, especially when hoped-for improvements are slow or fail to occur (Simons 1987). Professionals empathize easily at such times and may experience similar emotional reactions.

The destruction of what have been termed "highly valued dreams" by dismal facts produces predictable emotional results (Moses 1983). These include guilt, denial, and anger. Of these, only anger, and the aggression or hostility that can occur, has been adequately studied scientifically and understood in terms of its underpinnings in biologically based defensive reactions (e.g., Bandura 1973; Flannelly, Blanchard, and Blanchard 1984). The others, guilt and denial, are essentially cognitive phenomena. While less well understood, they represent highly reliable emotional effects of bad experiences, which also may have adaptive functions. Guilt may motivate problem-solving and independent action. Denial seems to work as a cognitive barrier to the perception of incapacitating or trou-

ling thoughts that might impede an ability to get on with essentials of day-to-day living (Meichenbaum 1985: 74-75); it allows people time to revise their priorities.

Selectively screening out bad news through denial allows people to carry on with plans and relationships that would otherwise have to be abandoned, but which may serve other valued functions. Not believing something that is true also has a darker side. It allows people to go on doing things that could be, in part, bad for someone (including oneself). This is especially problematic when some aspects of continuing a course of action in the face of contradictory information are good for the denier, but bad for someone else. When this is the case, harm can continue for as long as the person doing the denying derives benefit from the thoughts and actions the erroneous beliefs permit.

Denial, a form of avoidant coping, is recognized as a common reaction to the diagnosis of a serious illness or disability in oneself or a loved one. Margalit, Raviv, and Ankonina (1992) demonstrated that parents with disabled children requiring continuous special education differed from demographically similar parents in their increased use of avoidant coping and that they exhibited lower confidence in being able to control and understand their world. Interestingly, a greater tendency to adopt avoidant coping strategies did not appear to prevent them from using active coping strategies (i.e., more direct problem-solving). Rather, families with disabled children used a greater mix of the two problem-solving strategies. Further, families whose disabled children had more socially disruptive behavior seemed to use more avoidant coping than families whose disabled children exhibited fewer socially disruptive acts. These findings also are

consistent with the effects of chronic stress on the selection of coping styles.

Autism

Autism is a severe developmental disability, fortunately uncommon, but prevalent enough to merit specialized educational and habilitative services for affected individuals in even medium-sized communities. It occurs in 4 to 5 of every 10,000 children (Kiely, Jacobson, Schupf, Zigman, and Silverman 1989; Pueschel et al. 1988). It is normally a lifelong disability, associated with mental retardation in about 60 to 80 percent of cases, defined by seriously delayed and often qualitatively abnormal language and communication, and strongly associated with frequent behavioral abnormalities. Common abnormal behaviors include social withdrawal; ritualistic, self-injurious, or odd repetitive acts; and higher rates of asocial or aggressive types of disruptive behavior. A single neurophysiological cause has not been identified for the syndrome.

An additional tragic fact is that affected children are often otherwise quite normal in appearance, bearing none of the physical deformities associated with many other developmental disabilities. Hence autistic children are sometimes described as "beautiful," probably a poignant reminder that except for their decreased ability to learn many types of things, to communicate, and to interact socially, they are initially as likely to evoke positive emotional commitment from adults as any other children.

There have been a few signs of improved scientific understanding of how to help autistic children learn to behave and communicate more normally (Lovaas 1987), but the necessary techniques are costly and demanding

and not always effective. There is an active international research effort. Great strides have been made providing needed educational and medical services to these and all handicapped children in the United States (Pueschel et al. 1988). Still, there is no denying that anyone who works or lives with autistic children, especially when they are young, has the sense and the hope that with just the right nudge—or drug or treatment or environment or *something*—they will snap out of the syndrome and act as appealing and as normal as they look. Parents of autistic children must harbor such thoughts even more often than most of us; unfortunately, most autistic children simply do not snap out of it, or even improve, without much expense, training, and effort.

Parents of autistic children may be expected to employ avoidant coping styles more than most parents (Margalit et al. 1992) and to be highly motivated to obtain services that seem to help their children. For better or worse, these hopes are fueled by the implicit promise of our technological society and its cultural preference for hyping the amazing, the simple, and the ever more dramatic benefits of "discoveries" and "breakthroughs." This sets the stage for increased vulnerability to early adoption of untested and poorly conceived interventions and services.

Rescuers from Down Under

Enter Professor Douglas Biklen of Syracuse University with an imported miracle cure from Australia for the often utter failure of autistic children to learn to speak normally, a technique referred to as Facilitated Communication (FC). FC is "communication by a person in which the response of that person is expressed through the use of equipment and is dependent on the

Defacilitated Communication

Facilitated Communication is not cold fusion or N-rays. Professionals have advocated some form of what is now called FC for 20 years. The principle is unassailable: autistics have deficits in their communication skills and therefore require assistance to communicate—like providing paraplegics with wheelchairs to compensate for their inability to walk.

But the hard-core hysterics miss the point. They see FC not as a means, but as an end. The autistic, they say, will forever be dependent upon the facilitator. So even if the inflated claims for FC are true, what good is it? Unlike a wheelchair, one cannot take a facilitator along to school, to work, or on a family outing. Exchanging dependency upon a parent or caretaker for dependency upon a facilitator is no bargain for the autistic.

My autistic son is five years old. His teacher introduced him to FC at a computer keyboard several

months ago, and he was delighted. He needed no facilitator—he was capable of picking out the letters on his own and stringing them into words.

But the charms of the computer paled when his teacher introduced him to an infinitely more powerful and flexible medium: pencil and paper. Now he happily spends hours printing and tracing words. He does not speak, but is learning to write. Once he spontaneously hopped out of his seat, went to the blackboard, and wrote "MARK IS HAPPY." His teacher wept.

FC is merely a stepping stone. The goal is defacilitated communication. The goal is empowerment.

—Mark S. Painter, Sr.

Mark S. Painter, Sr., is a freelance science-fiction writer in Mont Clare, Pennsylvania, and an attorney.

assistance of another person" (Intellectual Disability Review Panel 1988: iv). FC procedures involve using graduated physical (manual) prompting, in an initial least-to-most-effort hierarchy, with gradual reduction of guidance, to help a person point to or strike the keys of a typewriter, a computer keyboard, or a paper facsimile. The intent is to support a person's hand sufficiently to make it more feasible to strike the keys he or she wishes to strike, without affecting the key selection. In practice, the manual guidance is maintained indefinitely, suggesting an opportunity for the

facilitator to exert continuing influence on key or picture selection by the person being facilitated.

Biklen has justified and advocated the use of this technique in the United States (Biklen 1991; 1992; Biklen, Morton, Gold, Berrigan, and Swaminathan 1992), an amazingly effective effort. FC has been given wide and relatively uncritical recognition in the popular press (e.g., Spake 1992; Whittemore 1992; in contrast to more skeptical treatment by Shapiro 1992) and scandalously credulous treatment in nationally televised news programs.

This "therapy" is currently used nationally with thousands of handicapped people each day at a likely direct cost of millions of dollars each month. Biklen has bolstered his arguments by developing a novel theory of autism based in reframing its root cause as a form of developmental apraxia (i.e., a disorder of voluntary control of movement). Scientific evidence for developmental apraxia in autism is lacking. Autistic youngsters are often characterized by *better*-developed motor than verbal skills, even real nonverbal problem-solving talent. This presents little conceptual difficulty for Biklen. He also appears to imagine that people with no prior evidence of acquiring letter-recognition skills can quickly begin typing out sentences of fairly complex grammatical structure, albeit with a little help from their facilitator, and indeed have had hidden literacy all along despite previous classification as severely mentally retarded.

A Feeble Professional Response

Speech pathologists are prominent in the clinical promotion of FC, especially via fee-for-service introduction of the basic procedures to parents and paraprofessionals directly involved in day-to-day care of people with handicaps. Two of the present authors (Mulick and Kobe) attended a presentation by a speech pathologist at a recent state autism meeting in Ohio. The speaker (Veale 1992) stressed that facilitators must enter the FC situation with complete trust and *belief* in the autistic person's communicative competence, with the intention that *together you can show others*.

Veale did not describe the FC training procedure in any detail. Apparently, you prop the keyboard up on an easel and hold the child's hand near the keys while having a verbal

or typed conversation. In fact, procedural detail was specifically characterized as unnecessary for such a "simple" procedure. Additional points made: (a) Clients might not seem to be looking at the keyboard. (b) Interfering behavior problems might need to be opposed with just-right amounts of *physical force* to prevent movement of the learner's hand away from the keyboard. (It was implied that eventually, through FC, patients will thank you for doing so, as one of Veale's own patients communicated even while apparently trying vigorously to escape her grip.) (c) Because true communication is not composed of factual questions and answers but, rather, of open-ended alternating comments, one shouldn't ask factual questions in FC training; instead, one should just be receptive to what is produced by the handicapped individual.

Veale did not caution the audience about possible facilitator influence. She used testimonial evidence in the form of transcripts of FC conversations and a guest appearance by a grateful parent. Although statements made in conference papers are relatively ephemeral, they can have an inordinate impact on the practices of paraprofessionals and parents who may not be skeptical of obtaining unexpected literacy (especially when they are led to expect it by conference presenters). These features have little resemblance to the valid training in instruction for handicapped people that we have seen (Matson and Mulick 1991).

Novice FC trainees may not be well informed about how to teach or modify behavior. When the advice given is inconsistent, it will surely induce different practices by different trainers. Whereas these vague instructions encourage trainees to believe they need not require clients to look directly at the keyboard, Rose-

mary Crossley (1992a), the originator of FC in Australia, states that looking at the keyboard is absolutely necessary. Whereas the foregoing descriptions of benefit suggest that substantial progress can be obtained rather quickly, Crossley (1992b), Crossley and Remington-Gurney (1992), and Biklen et al. (1992) state that basic competence (e.g., some understandable content) may require up to six months. DEAL (1992) states that six years may be needed to attain communicative competence.

Unfortunately, no measurable definition of "basic competence" is provided. All sources reviewed by us that favor the use of FC mention some person with autism who demonstrated unexpected literacy upon the first try with FC. Transcripts of apparent conversational content are the only evidence provided (e.g., Biklen, Morton, Saha, Duncan, Gold, Hardardottir, Karna, O'Connor, and Rao 1991). We feel that the perceived unexpected literacy and sudden communicative competence is likely due to facilitator influence in most, if not all, such cases.

Scientific Evidence and FC

There has been no adequate controlled veridical support for any of the crucial claims made by FC proponents. We are aware of no demonstration that complex and meaningful linguistic performance, independent of possible facilitator influence, has been obtained from people who had been diagnosed severely or profoundly mentally retarded using valid methods by qualified diagnosticians. Complex linguistic performance is highly correlated with IQ and level of functioning in people with mental retardation and autism. We are aware of no evidence for rapid emergence of linguistic

competence in individuals for whom a clear history of learning cannot be documented. We are aware of little support for a motor-impairment theory of autism. There is scientific evidence relevant to each point.

Because its claimed effects were so marked, so unexpected in the context of existing scientific knowledge, FC provoked academic research interest,

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first by the government and others in Australia and recently by a few behavioral scientists in the United States. Studies in Australia used message-passing (giving information to a nonverbal person while the "facilitator" was out of the room, and subsequently attempting to verify the nonverbal person's comprehension via the typed content of FC) or question-asking directed to the disabled person with masking of facilitator hearing by white noise. While there were isolated instances of apparent valid communication through FC, a review by Cummins and Prior (1992) concluded that the responses of all people tested in these studies were contaminated by influence over content by the facilitators.

Another message-passing evaluation study in the United States (involving 23 people) reported that the validity of communications could be confirmed for *none* of the participants,

despite the fact that all were believed to be conversing with some degree of ability by facilitators and therapists (Szempruch and Jacobson 1992).

A controlled study involving 12 clients (believed by their caregivers to have been routinely communicating via FC for some time) and 9 facilitators, by Wheeler, Jacobson, Paglieri, and Schwartz (in press), was more explicitly revealing. In a procedure where two stimulus pictures were employed, Wheeler et al. (in press) show that clients responded accurately with labels of the pictures only when the same pictures were seen by the facilitators. Sometimes clients were shown the same pictures as the facilitators; sometimes the pictures were different. Clients responded "accurately" with labels of some pictures even when the pictures were seen by the facilitators but *not* by the clients, revealing that the typing was *controlled* by the facilitators.

In yet another study, the recommended training sequence for FC was used over 40 sessions with 21 young people with autism (Eberlin, McConachie, Ibel, and Volpe 1992); the technique produced no unexpected literacy, and no client was able to better his or her measured expressive language skills using FC over the level that was obtained using controlled testing of these abilities verbally. At present, there are no scientifically controlled studies that unambiguously support benefits in expressive language function from taking part in FC for people with mental retardation or autism.

There have been controlled research studies of very successful communication training in toddlers and preschool-age children with autism using conventional methods (e.g. Lovaas 1987), more limited but still successful reports of speech improve-

ment in older children with autism (Schreibman, Koegel, and Koegel 1989), and growing recognition of effective nonspeech communication approaches. The use of computers with adapted input devices and electronic, printed, or synthesized speech output is well established with motor-impaired people (e.g., Cory, Viall, and Walder 1984; Demasco and Foulds 1982; Mulick, Scott, Gaines, and Campbell 1983). Appropriately configured and adapted computers have long been useful as instructional devices, communication tools, environmental control systems, and game platforms with special populations (Vanderheiden 1982), just as they are for everyone else. Other communication systems successfully used by people with autism include manual sign language and picture or idiogram-based systems. Clearly, the issue is not how communication is mediated, but whether or not it is controlled by someone else, whether or not there are at least two independent participants in a communicative transaction.

Motor Apraxia in Autism

The FC perspective directly challenges neuropsychological and linguistic perspectives, founded in a large body of scientific research, about the language of autistic people. Language is complex and involves elaborate neurological substrata. The speech and language of autistic people differs greatly from that of other people, presumably as a result of neurological impairment. While understanding of the spoken word by autistic people is consistent with their general intelligence, they tend to retain and use the meaning of what is said to them differently, without some of the social information that normally accompan-

ies language and that occurs without much effort for the average person. For example, people with autism who can talk have difficulty sharing nuances of meaning that involve taking another person's perspective. They also have difficulty expressing their emotions and accurately attributing emotions to others. These features greatly affect what autistic people say, how they say things, and in some ways, what they mean by what they say. The language of people with autism who have normal intelligence (and quite a few do) is more concrete, sometimes esoteric, and more oblique compared to the average person. The language of autistic people previously diagnosed with severe mental retardation, but now using FC and cited as examples of success, in contrast, is often rich in interpersonal subtleties well beyond the aspirations of many college English majors (but perhaps not beyond those of philosophically inclined teachers or therapists with master's degrees who promote FC).

How is all this viewed by FC proponents? The motor-impairment perspective on language function set forth in writings on FC is based on the concept of motor apraxia. Apraxia refers to the neurologically determined inability to voluntarily initiate behavior or movement (because one cannot "figure out" how to move). In contrast, the term *aphasia*, which was once the term used for problems in language, now is reserved for more strictly cognitive or conceptual problems in using language. Champions of FC believe that people who have autism are not affected by aphasia but, rather, by apraxia, which involves the neurological substrate of the movement system for organizing or performing speech. At the same time, they argue that autistic people have problems "finding" the words (especially nouns), which should be called

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dysphasia, and speaking the words, dyspraxia.

Neurological terms have specific meanings. What is described by FC proponents refers to difficulties, rather than inabilities, of people who are considered autistic, in using words in certain ways. The quandary in trying to understanding the propositions that proponents offer, in a largely post-hoc fashion, to explain the disorder and why FC is needed is complicated by the fact that they seem to confuse terminological distinctions. The prefix properly related to "difficulty" is *dys*, not *a*. If neuroscientists were to offer the same arguments that are set forth in articles advocating FC, they would consistently use the terms *dysphasia* and *dyspraxia*.

There is a great deal of evidence that what autistic people say intrinsically reflects the social character of much of their unusual behavior, how they seem to regard other people, and some features that might accurately be described as specific dysphasia(s) and specific vocal dyspraxia(s). Nevertheless, neurophysiological research has not yet demonstrated even a firm basis for a specific dysphasic disorder. However, aside from using terms that, as they are normally used, do not apply to the effects of autism on how people speak, FC proponents further suppose "global apraxia" characterizes autism: that affected people cannot voluntarily initiate movement. The usage

error, again, is that they mean autistic people only experience difficulty. Further, there is no research evidence at all to support the position that people with autism experience such global problems. The usual clinical finding, familiar to any psychologist who routinely works in this area, is that motor impairment and delay is much less prominent than communication disorder and delay (Jacobson and Ackerman 1990). In fact, when playing quietly, or simply walking or using a climbing toy, their relatively smooth and coordinated movement and lack of physical deformity is part of the reason autistic children look so appealingly normal and kindle such general interest and hope.

Surprisingly, although the media and disability advocacy groups have greatly promoted FC, little fundamental opposition by professionals to FC has emerged. Very little criticism has been voiced within developmental disability service agencies or regulatory bodies. Many seem to view FC as the greatest breakthrough of all time, the very breakthrough for which advocates interested in full integration of all handicapped people have been waiting so that no one will, by virtue of inability to express themselves, be deprived of a place in society. Many in disability services, who might be critical, understandably hesitate to be, probably for fear of rejection by those involved with FC every day at their place of work.

Why, at the same time, there has not been an aggressive and visible reaction by professional and scientific societies in medicine, psychology, and neuroscience is more difficult to explain. There are numerous pressing issues facing professionals and scientists in their own fields, many involving funding and competition for resources. It may also be that large portions of these professional and

scientific groups have abandoned issues related to people with chronic disabilities, whom they cannot cure, to the human service organizations and government agencies that vocally and confidently present themselves as meeting all disability needs. At the same time, toleration of marginal standards for care and quality by the learned professions serving disabled people does everyone a serious disservice. Ineffective services can be costly, unnecessarily increasing the strain on the nation's health budget. Further, it represents indirect support for the prevalent belief among growing segments of the public that health professionals and scientists are not truly to be trusted.

Conclusion

There is good reason to be skeptical of extravagant claims made for FC. Our impression is that, at best, it represents a false ray of hope for many families. Many parents and empathic, concerned paraprofessionals might be especially vulnerable to the appeal of FC because of avoidant coping styles or the action of cognitive denial mechanisms that reduce perception of some features of severe disability in others.

The promotion of FC diverts effort and funding from more plausible long-term strategies that have empirical support. The theoretical confusion gratuitously injected into the research and professional literature by FC proponents is damaging to accumulation of knowledge about handicapping conditions and their causes and detracts from the credibility of sincere efforts to integrate findings about abnormal development. The popular confusion of FC with other nonspeech communication systems that have been used successfully with disabled people will discourage public support

for these tried-and-true strategies when the FC bubble bursts. And burst, it will. In the end, regret will provide small solace. The irony of FC is perhaps best revealed by a poem reproduced in the Fall 1992 issue of *The Advocate*, a newsletter of the Autism Society of America (p. 16), a poem that won recognition for its author, identified as a 26-year-old youth with autism. The poem (despite its spooky resemblance to an old Beatles song) was said to have been produced via FC. Two lines, in particular stand out; it begins, "I am you, and you are me. . . .", and goes on, "... We are each other as we are what We can be. . . ."

The professional and scientific communities, as well as government human service and regulatory agencies, should not allow people with handicaps and their families to be used by a few professors and therapists who stoke their hopes with empty promises, regardless of their sincerity, while reaping personal or political rewards and working hard to prevent systematic verification of their claims. Such practices should always be called into question. In our experience, people with handicaps can be valued members of their families and communities without resorting to appeals to miracle cures. There is effective help available, help that makes scientific sense. The genuine efforts of scientifically trained and compassionate professionals surpass all fad treatments, and always will. Advances in treatment and understanding come at the price of rigorous training, dedication to accuracy and scientific standards, and objective verification of all treatment claims.

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James A. Mulick is professor of pediatrics and psychology at the Ohio State University. He was supported in part by the U.S. Department of Health and Human Services, Bureau of Maternal and Child Health Special Project MCJ 009053. He is a fellow of the American Psychological Association. He has been a clinician and researcher since 1975, working to improve access and quality in services for children with handicaps and their families. Write him at Department of Pediatrics, Division of Psychology, 700 Children's Dr., CHPB-4, Columbus, OH 43205-2696.

John W. Jacobson is an associate planner with the New York State Office of Mental Retardation and Developmental Disabilities. He recently served as national president of the Psychology Division of the American Association on Mental Retardation, as president of its Northeast Region X chapter, and organized the 1992 Northeast Region X meeting around an examination of Facilitated Communication. His address is 627 Plymouth Ave., Schenectady, NY 12308.

Frank H. Kobe is a fellow in pediatric psychology at the Ohio State University and Children's Hospital in Columbus. He has experience in a variety of developmental disability service agencies as a psychology service provider, researcher, and community residence agency board member.