

EDITOR'S NOTEBOOK

FACILITATED COMMUNICATION:

Problems, Puzzles and Paradoxes: Six Challenges for Researchers

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Facilitated Communication (FC) has become a very hot topic, not only in the world of autism, but in the public media. The *New York Times Magazine* published an extensive article on FC (October 6), and the CBS Evening News carried reports on FC on two successive evenings in mid-October. Judging by the calls our office continues to get from the other television networks and from various print publications, we can expect even more media attention in the future.

This is the fifth successive issue of the ARRI which has provided information on FC. Prior to the recent upsurge in interest in FC, and prior to the coining of the term "Facilitated Communication," non-speaking autistic persons who write had been described in editorials in ARRI Vol. 2, No. 1 ("Quantum Behavioral Improvement") and ARRI Vol. 4, No. 1 ("Autistic Crypto Savants"). The titles of these articles represented my attempts—unsuccessful, as it turned out—to direct attention to the phenomenon.

We oldtimers in the field of autism had known about, and talked about, autistic children who could communicate only in writing since the 1960s, but it seems the time was not right. Thanks to the diligent efforts of Rosemary Crossley of Australia and Douglas Biklen of Syracuse University, recognition of FC has finally arrived—with a bang.

It is easy to see why FC has generated so much excitement. Recently I received a phone call from the mother of a girl with both cerebral palsy and autism. The girl was thought by school officials to be hopelessly retarded. The officials were totally unwilling to believe the mother's assertions about the progress that the daughter was making using the keyboard of the family's home computer. The mother's insistence that the child be given intensive training suitable for autistic individuals met with stubborn resistance from the school officials, which led to a formal hearing on the matter. The hearing officer, after listening to both sides, could not decide who was right, so he hired as a consultant a professor of special education at a nearby university, to investigate the mother's claim that the daughter was able to communicate quite successfully through FC. After visiting the child at home and at school for several days, the professor wrote (the mother sent me a copy of his letter) that quite contrary to his expectations and beliefs, the autistic/CP girl was in fact able to communicate quite effectively and that the mother's demands that increased resources be devoted to her daughter were indeed reasonable.

Another excited parent sent me a package of materials written by his autistic son Rusty along with a note on chartreuse day-glo paper stating, "My 11 year old autistic son Rusty is a low functioning, non-verbal, not toilet trained boy who was labelled severely/profoundly retarded just six months ago by a school psychologist. But within the

last two months a miracle has occurred through facilitated communication. For the first time in his life we are able to have 'normal' conversations with him (see transcripts enclosed). Rusty has taught himself to read, he can add, subtract and multiply, and knows names, places, dates and times. He comprehends almost everything he reads or hears and appears to have a photographic memory. None of this we knew before, but he did. A recent evaluation by a speech/language pathologist (report enclosed) revealed language abilities above normal and receptive understanding of single words at the adult level . . ."

Why do low-functioning individuals using facilitated communication often appear to have much higher cognitive functioning than high-functioning verbal autistic individuals?

Exciting indeed, but the struggle is far from over. There are many questions that require answers before the ultimate promise of FC can be realized. Here are six questions/problems that I feel should receive priority attention from researchers:

1. **The reality of FC.** Enthusiasm notwithstanding, disbelief in FC is common. Properly conducted research would clear the air and increase acceptance. FC does invite disbelief. A Minnesota mother of a prime candidate for FC told me recently that she thinks FC is just a fad, based on hope rather than data. Hard-nosed research could readily be done: e.g., place 10 small objects (pencil, key, coin, comb, etc.) in a paper bag. The facilitator leaves the room and the autistic student watches while the experimenter randomly removes and displays three items from the bag. The items are replaced and the facilitator returns and uses FC to elicit the names of the three objects from the student. If this experiment were repeated several times with each of a dozen non-speaking autistic persons (one afternoon's work), precise mathematical probabilities could be calculated to determine the statistical reality of FC, at any preferred level of confidence. Videotaping the experiment would make the case air-tight and (hopefully!) give FC some needed credibility. To my knowledge this simple study has not yet been done in any formal way.

2. **Target population.** For what proportion of the non-speaking, severely impaired autistic population does FC work? Most of us had earlier assumed that only a small percentage of non-speaking autistics (those whom I referred to as "autistic crypto savants") had the capability of writing via

pencil or typewriter. Rosemary Crossley and Douglas Biklen obviously think the percentage is much higher. Biklen has been quoted as estimating 90%, a figure I regard as probably much too high, but no one really knows. A related question: what are the distinguishing characteristics of those for whom FC will work?

3. **The role of touch.** As Rosalind Oppenheim first noted in the 1960s, and Rosemary Crossley and others have since confirmed, many autistic individuals need to be touched by another human being, on their hand, wrist, arm or shoulder, in order to be able to communicate. Why? At the 1991 ASA conference in Indianapolis, neurologist Ralph Maurer mentioned that a similar phenomenon is sometimes seen in Parkinson's Disease, where voluntary activities cannot be initiated unless the person is being touched (grounded?) by another individual. Puzzling indeed!

4. **Paradoxical functioning.** Why do individuals who cannot communicate except through facilitated communication often appear to have much higher cognitive functioning, judging from their responses, than so many of the supposedly higher-functioning autistic individuals who *can* speak? It almost seems as though there are two forms of autism (at least two) which are really quite different in terms of the cognitive capabilities of those afflicted, with some of the non-speaking individuals perhaps having considerably greater cognitive ability, if it could be tapped, than those formerly thought to be higher functioning. The apparent level of self-awareness—and world-awareness—seen in many autistic persons enabled to express themselves through FC is, in particular, astonishing.

5. **Unaffected outcome.** Why does the ability to communicate through FC seem to have such little impact, in so many cases, on the long-term prognosis for the autistic person? Several autistic persons known to me who used facilitated communication in the 60s, and the two autistic young men (each named Michael) described in my autistic crypto-savant article, who were communicating by writing in the 1970s, have all remained very severely disabled, non-productive or barely productive, individuals. Their ability to communicate has made very little difference. Why? How can we improve their outlook?

6. **Protection from manipulation.** There is a real danger that a few facilitators, motivated by ideology or self-interest, may impose their own wishes, perhaps unconsciously, in the guise of FC. ("Tom told me he wants to move to a group home.") How can we best protect against such manipulation?

These six questions about facilitated communication are very salient in my thinking. I fervently hope that in the not-too-far-distant future significant research may be undertaken to help resolve these puzzling and paradoxical questions.

Researchers, please note!