

LETTERS TO THE EDITOR

Facilitated Communication

To the Editor:

Please cancel my subscription to the ARRI...I feel you are using scare tactics to discourage the spread of facilitated communication. I strongly believe you are causing more harm than good.

While there are some pitfalls in F/C, it still must be considered the biggest breakthrough that has ever happened. Your quarterly should be advocating F/C and telling others how to use it.

Jeffrey Smith
New York

To the Editor:

It surprises me to see that your notion of worthy journalism includes tabloid-type sensationalism from Australia. It further surprises me that you saw fit to persevere on the dismal "facts" not only once, but a few times in your related editorial regarding facilitated communication and the "horror story" of one person reporting sexual abuse.

Are we to believe that kids with autism never lie and if they ever do, we should all indict FC? Are we supposed to disbelieve FC because of this one horror story and the so-called "data" gathered in this one instance?

I detect something pernicious in your attitude about FC and wonder if perhaps because it is not something you championed early on, that you feel you need to undermine its validity somehow. Where is the mention of success stories here?

Ruth Buchanan
Denver

Editor's note: As most readers of ARRI know, I have "championed" F/C for several decades—long before it became well known. Two ARRI editorials were devoted to it before Douglas Biklen's now-famous article on F/C was published. Our last editorial on F/C (ARRI 6/1), which warned against abuse of F/C, mentioned not merely one case but seven cases of F/C being used to make unsubstantiated allegations of sexual abuse. Since then we have received pleas for help from desperate and embattled parents and teachers in New York (2), Illinois (2), Washington (3), and California (1). These people swear that the allegations are untrue, but it is extremely difficult for them to prove their innocence. I have received not only the "tabloid" articles from Australia that Ms. Buchanan mentions, which refer to many cases of F/C being used to make allegations of sexual abuse that were later found by the courts to be groundless, but also videotapes, including several cases featured on the Australian 60 Minutes show. In all cases known to me, including many cases in Europe, the courts have ruled against the allegations of sexual abuse made via F/C.

A recent newspaper article mentions 40

cases in the Syracuse, New York area of F/C being used to make sexual abuse allegations! One of these concerns a high-functioning girl with Down syndrome who speaks; the allegations, strangely enough, were made (by whom?) only through F/C.

F/C is clearly a tool that may help many handicapped people. It is also a weapon that may do irreparable harm to many innocent people.

To the Editor:

I am writing to endorse Dr. Rimland's suggestion that all parents and professionals involved with facilitated communication (F/C) carefully assess the extent to which "facilitated communications" actually represent the knowledge and ideas of the apparent communicator (i.e., the autistic child). In particular, I urge that they systematically evaluate the apparent communicator's ability to respond appropriately to information which is not accessible to the facilitator.

I recently had the opportunity to evaluate an autistic adolescent boy who has been using F/C with a trained facilitator. Based on the responses produced via F/C, his parents thought his cognitive and academic skills might be age-appropriate, and they were considering placing him in a mainstream classroom setting.

Knowing little of this boy's abilities, I felt compelled to test the assumption that the facilitated responses truly reflected his own knowledge and ideas. After hours of testing, with and without F/C, all the evidence strongly suggested that the F/C responses were heavily influenced by the facilitator. In brief, whenever the boy was asked to respond to a question to which only he (and not the facilitator) had access, the facilitated responses were inaccurate or inappropriate. For example, the boy could not perform simple arithmetic computations accurately, although previous performance when both he and the facilitator viewed the same information suggested much more advanced skills.

This boy has had enough trouble in his life—as have his devoted parents. The trouble added by false hopes and unrealistic expectations is a burden none of them should have to bear.

Lola C. Bogyo, Ph.D.
Gloucester, MA

To the Editor:

I was very pleased with this issue of ARRI. It made me quite happy that we had imposed some strict guidelines on the use of FC with over 50 clients in our program.

We have been struggling with validation and running into some problems. It does appear that there are some children for whom FC has some strong benefits. It also appears that there are some whose "miracle success" may be more the stuff of hope than reality.

There is one side benefit which I have seen that affected all of the children we serve. The positive view many facilitators express regarding the children they work with has had the effect of challenging those with limited views of the potential of children.

David F. Freschi, M.A.
Assoc. Executive Director, Autism Program
The Anderson School, Staatsburg, New York

B6, magnesium and DMG

To the Editor:

My son Jude, diagnosed with Pervasive Developmental Disorder before beginning a regimen of vitamin B6 and magnesium and DMG, has now improved so much that he is attending regular kindergarten! He is making steady and rapid progress toward normal speech, socialization and fine motor abilities.

I am very concerned by the FDA's plans to dramatically reduce the potency of vitamins and minerals, regulating high potency vitamins as drugs and eliminating supplements such as DMG. Legislation is now under consideration (HR3642/S2135) that would give the FDA such authority.

Even if megadoses of B6, magnesium and DMG would still be allowed by prescription, many doctors may refuse to write the prescription because doctors are taught in medical school that "there is no effective treatment for autism."

Darlene Hart
Metairie, LA

Editor's note: Agreed! Many people share the writer's concern. See editorial.

To the Editor:

My son Brian, who is autistic (age 23), has been receiving 1,000 mg. of vitamin B6 (and magnesium) since early January 1991. After about a month we started seeing real improvement.

Brian's major problem is ritualistic behavior. This can lead to self-abusive (mostly biting his hand or arm) and aggressive behavior (hitting, etc.). After a severe episode several years ago, the tantrums were more severe than usual, and his ritualistic behavior was totally out of hand.

The B6 and magnesium have really accelerated his progress — there have been no tantrums at all since we started the B6, and the ritualistic behavior continues to improve. About one month after starting the vitamin B6 and magnesium, we started giving Brian DMG, as well as the B6. We noticed right away that he used more language, was more social, less ritualistic, and for the first time in 23 years actually watched TV. I feel that the DMG and vitamin B6 and magnesium together have helped him immensely.

Recently, during a very hectic period, I forgot the noon and evening doses of DMG three days in a row. We noticed that Brian was more withdrawn, more ritualistic, and wasn't using language very much. When his regular dose was resumed, all of that disappeared. At that time, he was on a dosage of 375 mg.; now he is getting 750 mg., and we're noticing more improvement.

Brian has been on and off Mellaril since age 7, and we've never been able to keep him off the medication for long because of his severe problems with ritualistic behavior. He was receiving 100 mg., and now is down to 75 mg., and we hope to slowly bring that down until he is off of it entirely. I'm optimistic that we'll succeed this time.

Mrs. Mary Balliet
Vero Beach, FL