

## LETTERS TO THE EDITOR

### To the Editor:

After reading the ARRI article on facilitated communication I thought I would share some of our progress with this method.

Of a population of 76 children we currently have approximately 50 involved with facilitated communication at one level or another. While I think there is a great deal yet to be learned about the method and some solid work needs to be done on validation I am reasonably convinced that it is a significant contribution. Among the many highlights that we've seen with the method:

—Numerous children have been involved actively in the planning process for their IEPs.

—Two to three children have begun to give us feedback on how they feel about medication and how medication makes them feel.

—Several children have entered into productive peer relationships. One of our students will begin to serve on our Human Rights Advisory Board.

—Staff attitudes are undergoing significant changes.

David F. Freschi  
Assoc. Exec. Director, Autism Program  
The Anderson School, Staatsburg, NY

### To the Editor:

In the last two months a miracle has occurred for my 11-year-old autistic son, Rusty—who is "low functioning," nonverbal, not toilet trained, and labeled as severely/profoundly retarded—through facilitated communication. For the first time in his life we are able to have "normal" conversations with him. Rusty has taught himself to read, add, subtract and multiply, and knows names, places, date and time. A recent evaluation by a speech/language pathologist revealed language abilities above normal, and receptive understanding of words at the adult level!

Best of all, he can now "talk" to us. We know what he wants and is thinking (he even corrects us when we are wrong!). People are treating him as a real person for the first time. He is very happy and proud that people know how smart he is. He has even explained some of his "autistic" behaviors to us, and they are completely rational in light of his explanations.

Facilitated communication is easy and cheap. We use an old electric typewriter. Some use computers, and others use letter boards. Age is no barrier; in northern Vir-

ginia facilitated communication is being used with adults in sheltered workshops, also with amazing results. This is not a cure, but it may be the single most revolutionary breakthrough for nonverbal autistic people ever.

Thomas R. Brooke  
Springfield, VA

### To the Editor:

Some of our parents have been trying DMG (di-methylglycine), a non-toxic metabolite (see ARRI 4/2) It has been having very beneficial effects in the area of improving speech and concentration and interest in toys and games. I have tried it myself over about a month, and it does help my son's concentration, and his speech, although repetitive, is coming on. Even his teacher says how verbal he has become.

Brenda O'Reilly  
Allergy Induced Autism Group  
Reading, Berks, UK

*Letters to the editor are welcome. Letters intended for publication must be signed and should not exceed one page including references. Letters may be edited without consulting the authors.*

## COPING: how parents, siblings deal with autism

(continued from page 6)

that such parent-training programs themselves, while of great benefit to both parents and autistic children, can be stressful if professionals' expectations are unrealistic. Professionals "cannot expect to change the behavior of a child without having an effect upon everyone else in the family," they caution. "For example, if a parent is recording episodes of self-injury, making bathroom checks every half hour, and demanding speech during every encounter with his or her autistic child, there will be less time for meal preparation, PTA meetings for the other siblings, or an evening out. These shifts in the allocation of energy will have a direct, often negative, impact on every member of the family." Bristol agrees, saying that professionals should encourage "a family-oriented rather than an autistic-child-centered home."

A 1991 Canadian study by Sandra Fisman and Lucille Wolf found that raising an autistic child is more stressful than raising either a non-disabled child or a child with Down syndrome. The researchers tested parents of 124 children (31 with autism, 31 with Down syndrome, and 62 with no disabilities), and found that mothers of autistic children scored significantly higher on measures of depression (with scores of the Down syndrome group falling between the control and autistic group scores). While fathers appeared less affected, the researchers say that "[they] nevertheless . . . appear to be particularly vulnerable to the stress generated by these difficult children."

Fisman and Wolf found parents' stress

was linked to autistic children's lack of adaptability and resistance to change; their lowered acceptability, because of their odd behaviors; and their demandingness. They also found that social support was the most important "stress buffer" for parents. Rodrigue found that compared to mothers of non-disabled children, "mothers of both autistic and Down syndrome children reported more caretaker burden, restrictions on family travel, more last-minute changes in plans, and a greater focus on short-term plans versus future-oriented goals."

A 1991 study by Pattey Fong suggests that parents' level of stress is related both to actual circumstances (such as the child's level of behavior problems, and the number of available services), and to how the parents themselves perceive events. High-stress mothers were more likely to have negative reactions to videotapes of autistic individuals doing daily activities ("he might cut himself," "she's going to have a tantrum"), while low-stress mothers tended to have more positive or neutral reactions ("he looks happy"). "The results are consistent with findings from the general stress literature demonstrating that emotional responses may relate more directly to the types of cognitive appraisals people make than to the objective characteristics of the stressors," Fong concludes.

In spite of the day-to-day stress of raising an autistic child, the majority of families appear to be coping well or even thriving. A 1983 study by Robert Koegel et al. found no significant differences in stress or psy-

chological health between mothers of autistic children and well-adjusted control-group mothers, and a 1984 study by Akerly found that the divorce rate in families with an autistic child was actually significantly lower than the national average. Bristol, too, found that the families she studied were very similar to well-adjusted families of non-disabled children, with two exceptions: a "markedly higher moral-religious emphasis," and a lower level of participation in social and recreational activities (probably due to the disruptive nature of their autistic children's behaviors).

In general, Bristol found, the keys to coping with an autistic child included "a close-knit, supportive home environment, being able to express feelings openly, and actively participating in activities outside the home." Bristol found that "the lowest stress mothers reported greater perceived support . . . [including] support from spouse, immediate and extended family, friends, and other parents of handicapped children." In particular, she says, a supportive husband and relatives were critical. She adds that parents receiving intensive support services, such as the variety of programs offered by the TEACCH program at which she works, had significantly lower stress levels than mothers in programs providing few support services.

A list of the references used in preparing this article is available upon request. Send self-addressed, stamped envelope to ARRI and ask for references for "Families" article in Volume 5, Number 2.