

LETTERS

(continued)

To the Editor:

In response to "Community, My Foot," I can say RIGHT ON!! For eight years I was director of Rehabilitative Therapies at Arizona State Hospital. We had excellent programs including work evaluation and placement and many programs preparing people for life in the community. We saw all that go down the drain in the name of deinstitutionalization. We saw former patients end up in jail, people who were in no way capable of being held responsible for their actions. Many, many more have ended on the streets, hungry, without shelter, leading miserable existences, not able to understand. Do they appreciate their "freedom?"

I share your concern about the moves by well-meaning people to try to legislate what kinds of settings should be available for autistic individuals.

Lorna Jean King, O.T.R.

PDD: another view

To the Editor:

[Re] "The PDD Issue: What's In a Name?" (ARRI 5/2), the letter [summarized in the ARRI and published in *Developmental Medicine and Child Neurology*], signed by 16 leading specialists in the field, begins with a ringing affirmation that "the inclusion of childhood autism among the developmental disorders in the late 1970s was a major step forward." With this observation we wholeheartedly agree.

After this clear-cut declaration, however, the letter proceeds along a far more tangled line of thought. Its authors question whether autism and autistic-like conditions are necessarily "pervasive," particularly when retardation is not present.... The DSM-III-R defines "pervasive" as covering the areas of social skills, communication skills, cognitive skills (in particular imaginative activities), and often the development of motor and sensory skills — precisely the multiple areas of disorder which the Autism Society of America has always cited in its standard definition. Yet the authors of the letter... seem to use the word "pervasive" in its most extreme dictionary sense: referring to a quality which affects all aspects without exception. Judged by this impossible yardstick, of course, autism would surely not be pervasive. Perhaps the only truly pervasive disorder would be death itself.

The realization that we are dealing with lexical issues, not DSM issues, throws light on the authors' insistence that the PDD label presents an acceptance problem for high-functioning individuals with autism: "...how can we confidently tell them and their nearest that they have 'pervasive developmental disorder' or 'PDD'?" If "pervasive" were taken not in its clinical sense but its ultimate dictionary sense, it might indeed be distressing to suggest that an individual is impaired in every possible way! Having

fielded [many] phone calls [for the Greater Philadelphia Chapter of ASA], we hasten to testify that we do confidently speak with them and their nearest about the *clinical* meaning of PDD. In fact, the vast majority of our callers have already received a PDD diagnosis and seem pleased to have a neutral, standardized descriptive term.

The authors also evince concern that PDD terminology has not caught on in clinical practice or among the public. It isn't so in Pennsylvania, or in many other states of which we are aware. The fact that 12 of the 16 authors practice in Europe causes us to wonder whether the diagnostic issues being debated in Europe may not be directly comparable to those on the table here at home.

Patricia A. Amos
Virginia Leonard, P.A.A.
Joan Bergquist, P.A.A.

Editor's Note: I strongly disagree with the above views on PDD. Many hundreds of parents, who have told me their child was diagnosed as "having PDD," have been pleased and relieved when I responded that PDD is a meaningless, ill-conceived label derided and scorned not only by me but by most professionals knowledgeable about autism. To the letter writer's complaint that sticking to the dictionary definition of pervasive is somehow "extreme"—I say, "Nonsense!" Like most people, I think pervasive means pervasive and not something else. I support the 16 autism experts who wrote the anti-PDD let-

ter. My editorial on the silliness of the PDD terminology will appear early in 1992.

Vitamin B6

To the Editor:

As the assistant manager of a vocational program, after hearing a lecture by Dr. Rimland, I suggested trying one of our middle aged woman clients on high dosage vitamin B6 and magnesium.

Carol was nonverbal and had many difficult fixations and problems, such as flipping up visors in parked cars as she walked by, moving office desks, and throwing items in inappropriate places. Correcting these behaviors caused screaming, biting and stamping.

On the vitamins, Carol now carries out most of her tasks independently. Staff no longer fear waiting in line with her or going to grocery stores. She accepts constructive criticism. Her speech pathologist has become very excited about her progress, both verbally and gesturally. Everyone is very impressed. Neither the speech therapist nor her employer, who says she's made remarkable progress, knew about the vitamin program.

If your readers have any doubts about pursuing the use of vitamin B6 and magnesium with adults, please make the effort. Our experience would say you have nothing to lose and everything to gain.

Stephanie Campbell

Editor's Note: For information about B6 and magnesium (and also about DMG, another safe nutrient), write ARRI.

How autism feels: an "inside report"

How does it feel to be autistic? What does an autistic individual see, hear, and remember? In a new article, Laura Cesaroni and Malcolm Garber offer a fascinating look at autism through the eyes of autistic individuals.

Interviewing two high-functioning autistic adults, Jim (a 27-year-old currently completing graduate studies in psychology) and Albert (13 years old), Cesaroni and Garber asked them about many of their autistic behaviors. Among their responses:

—Sensory stimuli are often so intense that they are "overwhelming and confusing." In addition, sensory input can be oddly distorted; for instance, Jim commented that "sometimes the channels get confused, as when sounds come through as color." Jim also commented that it was not loud noises themselves that frightened him, but rather the disoriented feeling—perhaps similar to an epileptic seizure—which followed them.

The researchers note that the "multi-channel" sensory experiences of Jim and other autistic individuals merit more study. It's possible, they say, that individuals like Jim may be "gifted in their ability to perceive an extended spectrum of information from a given stimulus—much like observing ultra-violet or infra-red radiation, which are beyond the usual range of visual receptivity."

—Both individuals had exceptional memories, and it is possible that Albert even

remembers his own birth, since he related events about the birth that family members had not told him.

—Both individuals are making an effort to control their stereotypic behaviors such as spinning and rocking, but Jim reports that trying to control these behaviors makes him guarded and anxious. He comments that "stereotyped movements aren't things I decide to do for a reason; they're things that happen by themselves when I'm not paying attention to my body."

—Both Jim and Albert desire relationships with others, but Jim points out that this requires enormous energy on his part. The researchers note that he has "difficulty distinguishing different social roles played by the same person"—for instance, a boss who also made social advances toward Jim. He also has difficulty understanding conversations, he says, because he can only use words "when they mean what they mean."

Noting that both Albert and Jim express a strong desire to make friends, Cesaroni and Garber say that it is of "paramount importance" for others to look beyond autistic individuals' strange behaviors and recognize their need for social contact.

—
"Exploring the experience of autism through firsthand accounts," Laura Cesaroni and Malcolm Garber, *Journal of Autism and Developmental Disorders*, Vol. 21, No. 3, 1991. Address not listed.