

## EDITOR'S NOTEBOOK/Bernard Rimland, Ph.D.

## The second great autism watershed

Judging from what I have been seeing and hearing in the past year or so, another big change is taking shape in the world of autism. It seems to me that, as never before, parents are starting to take responsibility for their children's future. That is a very promising development.

The first great shakeup in the autism world took place a quarter of a century ago when the parents discarded the chains of guilt by rejecting, after decades of oppression, the "blame the mother" dogma preached by psychiatry. I am proud that my book *Infantile Autism: The syndrome and its implications for a neural theory of behavior* (1964) played a large part in that revolution. David Katz reported in 1979 that "ninety percent of the people in the field agree that Rimland's book blew Bettelheim's theory to hell."

The second revolution is a welcome and long-overdue extension of the first: parents are taking a much stronger and more active role in determining what is done to help their children. Note that I say "determining," not "advocating." Parents have always advocated—the difference is that now, increasingly, they are deciding and acting, rather than requesting or pleading. These changes are taking place on both the educational and biological fronts.

**Intensive early intervention.** Nowhere is the new activist stand more evident than in the explosion of intensive early intervention programs. The early issues of the ARRI chronicle the beginnings of this movement. ARRI 1/1 reported "the first published results of the UCLA 15-year followup study of autistic children given intensive 40-hour-per-week behavior modification." Forty-seven percent of the intensively taught children were successfully mainstreamed, compared to only one of forty students in the matched control groups of children who received less intensive behavior modification. The study provoked controversy (see ARRI 1/3), but that did not deter parents of young autistic children from trying intensive behavior modification. (See also ARRI 7/1.)

In other articles (ARRI 1/1, 6/2), we reported the results of the Princeton Child Development Study, which also showed extraordinarily good results for autistic children given intensive early intervention.

There were no guarantees, but there was opportunity. Here was evidence that young autistic children could be helped. Don't wait—act! Parents started their own home-based programs, using the Lovaas *Me Book*, and using whatever local resources they could muster from contacts within the psychology departments at local colleges. More recently, the early intervention movement was given major impetus by the publication of Catherine Maurice's superb book, *Let Me Hear Your Voice*. Two of the three Maurice children had been diagnosed as severely autistic by the best known clinics in New York City. Their mother's book provides a beautifully-written, day-by-day, detailed account of her struggles and the eventual recovery of both children, primarily

through the medium of intensive early behavior modification. The text and appendices have provided both inspiration and information to innumerable families with young autistic children world-wide.

And it is working! I have heard from scores of parents that they have instituted similar early intervention programs, by hook or by crook, home-based or school-based, almost always with excitingly positive results. Good news indeed!

**Biological interventions.** Parent activism has also accelerated dramatically on the biological front. As readers of the ARRI know, I have repeatedly called attention to the excellent results which are often seen by parents who try high-dosage vitamin B6 and magnesium, and/or dimethylglycine (DMG) on their autistic children and adults. These are natural substances, found in small amounts in food, do not require a prescription, and are immeasurably safer and more rational than any drug. In the case of B6/magnesium, there are now 18 consecutive published studies showing benefit to autistic persons, and none showing harm. Recently there has been an enormous upsurge in the number of parents reporting that they have tried B6/magnesium and/or DMG, often with good or even spectacular results. Adverse effects are very uncommon, never serious, and always short-lived. Lately, in addition to parents trying B6/magnesium and DMG, I have been hearing about trials of other natural substances—again with considerable benefit, in many cases, and no significant ill effects. The list of parent-initiated experiments with nutritional supplements includes trials of vitamin C, folic acid, carnitine, coenzyme Q10, taurine, and melatonin, among others. (Melatonin is a hormone, rather than a nutrient, but it can be bought without prescription from health food stores, and some parents report good results, especially in children with sleep problems, when given only one to three 3mg tablets of melatonin per day.)

What is the proper dosage range for these substances? I don't know, but I am trying to find out. If you have tried, or are trying, any of the above substances, or any other naturally-occurring, non-drug nutrients, herbs, or quasi-nutrients on an autistic child or adult, please write me with information on the size of the person, dosages used, duration of trial, time before effects were seen, and nature of the effects seen, both positive and negative (especially if any negative effects are seen). When I have enough information to make informed suggestions, I will provide it to our readers.

What accounts for the sudden upsurge in parent-initiated trials of nutrients? There are several factors:

1. The excellent results often reported for B6/magnesium and DMG, with no significant adverse effects.
2. The long series of failures of highly-touted "wonder drugs" for autism, and the high frequency of toxic side effects.
3. General disillusionment with orthodox

medicine. (Last year the *New England Journal of Medicine* reported, with some alarm and dismay, that 33% of Americans had turned to practitioners offering alternative health care methods.)

4. Fear—well justified, unfortunately—that if the FDA is not soon reined in by Congress, the public will no longer be free to buy the nutritional supplements and other non-drug substances that they are now trying out on their autistic offspring.

**Parental disempowerment.** Lest we get too euphoric about parental muscle-flexing, let me mention an unfortunate counter-trend: parents' rights to make decisions for their handicapped children are increasingly being usurped. Recently many parents have begun to report that they have been ignored, bypassed, and even blatantly overruled, in some cases, by school officials, social workers and other representatives of various bureaucracies. These people will tell you that your child's philosophy happens to match theirs, but not yours, with regard to sexual freedom, drug use, where to reside, and so forth. This deplorable situation is one outcome of the rise of advozealotry that I decried in a recent ARRI editorial (ARRI 7/4). Pretend that the handicap is not real—assume it out of existence, and it will somehow disappear, the advozealots believe. My advice to parents confronted with this problem is: don't buy it! Tell the officials in no uncertain terms that you, not they, are responsible for your child, and you do not join them in their fantasy that your child is not truly handicapped.

## Update on the FDA

The battle is by no means over! If you want to protect your existing right to purchase nutritional supplements without interference from the FDA, please continue to write and call your Congressmen and Senators, to make it very clear to them that you do not want the FDA to have any additional authority over your right to purchase supplements.

The last Congress adjourned without taking official action on this matter. The FDA, recognizing the strength of the public outcry against their attempts to restrict the sale of nutritional supplements, has attempted to convince Congress, and the media, that they really mean no harm. Don't trust them. If they were really sincere in claiming that they do not want to deprive the public of its right to purchase nutritional supplements, they would have long ago returned tryptophan to the market, now that it is clearly understood that the harm that was caused was done by a contaminant in one batch of tryptophan, and not by the tryptophan itself. Tryptophan has been taken off the market for about four years now, and there is absolutely no justification for that.

Since there are approximately 150,000 deaths each year in the United States as the result of the use of prescription drugs, and 0

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