

LETTERS

(continued from p. 6)

progress when treatment is discontinued and an apparent increase when treatment is resumed.

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To the Editor:

Many parents have told me that Lovaas lessons are often more effective if done while [an autistic] child is swinging or having pressure applied to him or her. This is especially true for children with very bad receptive speech.

Obviously not all the lessons [should] be done while doing sensory integration activities but several fifteen minute sessions per day is very helpful. I have had over fifty parents and teachers tell me that a child will often start talking on a swing.

The OTs need to do proper experiments to document efficacy. I have been after them to do that for years.

Temple Grandin

Editor's note: Temple Grandin's letter included several research papers. Among them was one citing a 1990 study by Imamura et al., who studied pressure therapy on 9 children with autism or pervasive developmental disorder (using Grandin's "squeeze machine"). The researchers found that hyperactivity was reduced in four of the children, while the therapy had no effect on the other five. One child began rolling himself in a quilt to achieve the same sensation when the machine was not available.

Incidentally, the Journal of Abnormal Child Psychology recently (Feb. 1995) ran an article on innovative treatments, which included a report on the "deep pressure" therapy used by Grandin and others. The article, by Eugene Arnold, concluded that "well controlled research [on the procedure] seems indicated from the public health perspective" because of its safety and cost effectiveness, as well as preliminary research suggesting its effectiveness.

Sandy Glovak included, along with her letter, an excellent review of several studies on sensory integration therapy. Unfortunately, the studies—like many others on this treatment—contain a number of methodological flaws. And their results do little to clarify the issue of whether or not sensory integration therapy is effective: some studies reported no little or no effects of the therapy, while others reported positive results. And, as Glovak points out,

Correction

In ARRI 9/2, there was a typographical error in the telephone number for the National Vaccine Information Center. The correct number is 703-938-0342.

studies tend to evaluate one small aspect of sensory integration therapy rather than the "total approach." The call by Glovak and Grandin for better controlled, better designed studies of sensory integration therapy should be heeded.

Early Intervention

To the Editor:

[Re recent reports on the effectiveness of early intervention programs for autistic children:] A bound packet containing the known legal cases from across the United States supporting school district funding for home Lovaas programming for pre-school children with autism, PDD, or PDD-NOS is available. Parents can send a letter request and check or money order, payable to Mary Jane White, for \$18, to cover the costs of material, printing and mailing, to:

Mary Jane White
405 West Main Street
Waukon, IA 52172

The packet itself was prepared and printed February 10, 1995, by Iowa Protection and Advocacy attorney Curt Systma and his paralegal, Ms. Swenson. It may be of assistance to parents in either preparing for or avoiding an IDEA due process hearing to obtain reimbursement for the expense of running a home Lovaas program for your pre-school child.

Mary Jane White, Attorney
Waukon, IA

Celiac disease

To the Editor:

There is a growing body of research that supports the experience of many parents that a gluten- and casein-free diet improves the behavior of their autistic children. It is critical that any parent considering this dietary intervention carefully read background materials BEFORE trying the diet, because:

a) A gluten-free diet (free of wheat, oats, barley, and rye) is extremely difficult to implement, even with cooperative children. Sources of gluten are hidden in many foods, and it is impossible to remove all of it without careful instructions.

b) Many parents report that even small amounts of gluten or casein (a milk protein) are sufficient to remove the majority of the benefits, and in some cases several weeks or months are necessary until clear benefits are seen.

c) Both of the major screening tests for celiac disease, a very serious form of gluten intolerance, will no longer be accurate once your child has started a gluten-free diet.

Two separate bodies of materials are available on the Internet to assist parents in this area. There is a general discussion group on autism at:

AUTISM@SJUVM.STJOHNS.EDU

To subscribe, send an e-mail to LISTSERV@SJUVM.STJOHNS.EDU with the body SUB AUTISM YOUR-FIRSTNAME YOURLASTNAME. Unfortunately, the topic of gluten and casein intolerance is not often discussed. However, this is a good forum to report your own ex-

periences, in that it will generate interest with other parents and researchers.

There is a second resource of about 725 celiacs (as of 9/1/95) which contains many crucial materials. Celiac disease is due to a pathological inability to completely digest gluten. Although many researchers suspect it is related to autism, it is clear that most celiacs are not autistic, and most autistics do not have full-blown celiac disease. Nevertheless, the steps which every celiac must go through each day—keeping gluten out of the diet—are the same steps which many parents of autistic children go through. Therefore, many of the subscribers to the celiac discussion group are not celiacs, but parents of autistic children.

To subscribe to the celiac discussion group, send an e-mail to:

LISTSERV@SJUVM.STJOHNS.EDU
with the body SUB CELIAC YOUR-FIRSTNAME YOURLASTNAME. There is no cost to you, unless your Internet provider charges you for the additional time on-line. Once you have subscribed, there are three sets of files which are highly recommended. To get these, send an e-mail to LISTSERV@SJUVM.STJOHNS.EDU with the body (on separate lines):

GET NEWCEL PACKAGE
GET CELIAC FAQ
GET CEL-AUT PACKAGE

The first two sets of files will teach you the basics of maintaining a gluten-free diet and finding a local celiac support group. The third set of files is a compilation of writings specifically on gluten and casein intolerance in autism, with many references and comments by other parents on their experiences. Also included is an electronic version of Lisa Lewis' excellent summary of the field. There are over 100 pages in total!

For those of you who do not have Internet access, ARI has secured the permission of the listowners of the celiac discussion group to print out these packages and sell them for the cost of photocopying and handling. To get them, send \$12.00 to ARI (Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116) and ask for "Celiac/Autism Package." Please note that although the Internet allows these materials to be continuously updated, ARI will only print them out semi-annually.

Brian Todd

DONATIONS NEEDED

The Autism Research Institute needs your help. We depend on the generosity of friends, families and organizations—not the government—for our support. Gifts, bequests, grants, and *in memoriam* donations are gratefully received and promptly acknowledged. There is much that we could accomplish if we had sufficient funds. All donations are tax-deductible.