



Early Intervention Training Institute
Rose F. Kennedy Center ■ University Center for Excellence

Winter 2005 - 2006

CONTROVERSIAL THERAPIES IN THE TREATMENT OF YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES: MEDICAL PERSPECTIVE

Merryl Schechtman, M.D.

INTRODUCTION

The increased access to therapeutic information through the Internet has contributed to the increased use of Complementary or Alternative Medicine (CAM). In 1992, Congress set up the National Center for Complementary and Alternative Medicine (NCCAM). The National Institutes of Health (NIH) defined CAM as: "*Health Care practices outside the realm of conventional medicine, which are yet to be validated using scientific method.*" The push in medicine is treatment based upon evidence of success (evidence-based medicine), yet there is also the pull of more unconventional or novel approaches to treatment. CAM refers to Complementary (added to traditional practice) or Alternative (used instead of traditional practice) approaches. The NCCAM identified five domains of CAM therapies: Alternative Medicine (e.g., Chinese Medicine), Biologically-Based Therapy (e.g., Megavitamins), Mind-Body Interventions (e.g., Meditation), Manipulative and Body-Based Therapy (e.g., Sensory Integration Therapy) and Energy Therapy (e.g., Magnet Therapy).

FACTORS LEADING TO THE USE OF CAM

Factors which influence parents to choose alternative therapies are often based upon the complexity of the developmental diagnosis. The more unfavorable the prognosis of a child's disability, or the inability to guarantee success with standard therapies, the more likely a parent is to seek a complementary or alternative therapy. Parents may opt for these therapies: if their child's medical provider is unfamiliar with the developmental problem, if adequate resources are unavailable, or if teachers or therapists, who have established emotional ties with the families, make recommendations for these therapies. Certain cultural and religious practice must also be taken into account as a factor in the use of CAM (Eisenberg, 1993). The

prevalence of reported use in the general pediatric population is only between 11-21% (Eisenberg et al, 1998; Ottolini et al., 2001). However, in treatment of children with cerebral palsy, 55% of parents reported the use of CAM to treat the child's tight muscles (spasticity), and 50% of children with autism receive some form of CAM (Nickel, 1996).

Alternative treatments have flourished for a variety of childhood disorders and have been especially prevalent in the treatment of autism and attention-deficit hyperactivity disorder (ADHD). These two disorders are chronic and tend to be difficult to treat. The body of this article will focus on some of the alternative therapies in these conditions.

TREATMENTS FOR AUTISM:

Biologically-Based Therapies:

- (1) **Elimination diets** remove certain food products from the child's daily diet. These diets are based upon presumed food allergies alleged to be the cause of the child's developmental problem. For example, elimination of casein (found in milk) and gluten (found in wheat) has been described. This is based on the theory that children with autism have leaky gut linings that allow absorption of compounds, which can alter behavior.
- (2) **Vitamin B6** supplementation presumes to affect brain metabolism and is felt to affect attention. It is often given with magnesium in the hopes of improving language function.
- (3) **Dimethylglycine**, also known as Panthothenic acid or vitamin B15, is a food supplement felt to improve language skills based upon an older report from Russia.
- (4) **Omega-3 fish oils** or essential fatty acids are presumed to affect the transmission of nerve impulses in children with short attention spans. Recent studies indicate that these oils may, in fact, prove to be beneficial in these children.
- (5) **Pepcid**, a medication to reduce stomach acid production, has been used to prevent what is presumed to be a more leaky or permeable gut in children with autism.

- (6) **Antifungal or yeast therapy**, including diet and medication, is based on the theory that some developmental disorders are caused by the overgrowth of yeast in the colon.
- (7) **Intravenous immunoglobulin** treatment for presumed immune weaknesses is based upon the history of developmental regression in up to one third of children with autism, creating a concern of possible immune factor deficiency in autism.
- (8) **Secretin**, a protein hormone derived from the pancreas, once believed to resolve symptoms of autism, is based upon a small series of case histories. However, when studied using scientific method, over 12 controlled studies failed to reveal treatment response.
- (9) **Chelation therapy** involves the removal of heavy metal toxins. This is based on a theory that heavy metals such as mercury lead to autism-like symptoms. Sources of mercury could include certain types of fish and thimerosal, a preservative, used in preparation of vaccines. Numerous studies both in the US and abroad have failed to support this theory. Additionally, thimerosal has been eliminated from vaccines since 1998 without any documented decrease in the incidence of autism.
- (10) **Withholding vaccinations** is based upon the theory that exposing the immune system to multiple antigens (proteins) such as those found in the measles, mumps, rubella vaccine (MMR), will overwhelm the child's immune system.

Manipulative and Body-based Therapies

Sensory Integration Therapy is a therapeutic approach developed by Ayres (1972), who suggested that inefficient neurological processing of information received through our five senses causes problems with learning, development and behavior. In particular, the areas most affected would be the vestibular (balance), proprioceptive (muscle stability) and tactile (touch) areas. Deficits would include: poor motor planning causing motor clumsiness (dyspraxia), abnormal posture (tone), hypersensitivity or hyposensitivity to incoming sensory stimuli (difficulties with textures, foods, labels, sounds, etc.). Sensory integration therapy purports to improve adaptive function to one's environment by providing appropriate sensory input through series of exercises and activities, as well as manipulating the child's environment to prevent over/under stimulation. Controlled studies, however, failed to show improved academic achievement or increased motor development. Sensory integration also did not reduce ritualistic behaviors. It did provide physical activity in individualized settings, but there

was lack of objective evidence to endorse it as a primary intervention. Despite the lack of evidence, it is a therapy that remains in high demand.

TREATMENTS FOR ADHD

Biologically-based Therapies:

- (1) **The Feingold Diet** is a diet based on a theory that salicylates found in food dyes and flavorings contribute to the symptoms of ADHD. Although objective studies have never confirmed this theory, a small subgroup of children with ADHD may respond somewhat positively to this intervention.
- (2) **Amino Acid and Megavitamin therapy** have not been shown to have compelling results in diminishing the symptoms of hyperactivity, impulsivity or distractibility.
- (3) **Herbal remedies** such as ginkgo-leaf extracts (memory), valerian root (insomnia), chamomile (relaxation) and lemon balm (relaxation) are frequently used in the form of tea and are purported to decrease the symptoms of ADHD.
- (4) **Iron therapy** has been used in children with ADHD and low levels of iron. Parents whose children have been on iron therapy have reported improved behavior; however, reports from the children's schoolteachers did not reveal any reduction in ADHD symptoms when the children were supplemented with iron.
- (5) **Homeopathic treatments** using tiny amounts of Stramonium niger (for nervousness), Cina (for restlessness) or Hyoscyamus (for poor impulse control) are commonly used treatments with variable response. Again, there are no documented objective studies of efficacy.
- (6) **Dietary supplements** which include essential fatty acids (evening primrose, flaxseed oils, omega-3) are felt to aid normal nerve transmission. Newer objective studies are suggesting positive findings. These supplements may become approved in the near future.
- (7) **Graphine**, an antioxidant felt to improve memory and recall, has had some equivocal response, but has not been studied well.
- (8) **L-glutamine**, an amino acid, is needed for normal concentration and is felt to be at subnormal levels in children with ADHD.

Mind Body Therapies in ADHD

- (1) **EEG Neurofeedback** or neurotherapy, has become a popular therapy purporting to reduce ADHD symptoms by attempting to change the type of neuroelectrical activity in the brain from a high frequency Beta EEG activity to a low frequency Theta EEG activity. Advocates insist that this type of biofeedback training has an 85%

rate in reducing ADHD symptoms. However, the use of neurofeedback is very expensive and there are no studies to indicate whether effects are sustained.

- (2) **Martial Arts** have become popular as a therapeutic intervention felt to have a more prolonged effect on behavior. These interventions have only anecdotal support, however.
- (3) **Interactive Metronome** is a popular treatment using biofeedback and requires hours of training at a great cost with only equivocal results.

SUMMARY

The use of complementary and alternative medicine is increasing, especially among children with chronic or developmental problems. To best serve the needs of these children and their families, a clinician should be familiar with the various CAM approaches and evaluate claims of effectiveness. It is crucial to identify potential harmful effects (e.g. peripheral neuropathy with vitamin B6 toxicity, liver toxicity with vitamin A, heavy metal toxicity with certain Santeria (or other cultural practices), and to provide information to families about all treatment approaches.

Families and clinicians feel the pressure to do something for the child. However, the family needs to understand that more intervention is not necessarily better and that many unconventional therapies are not proven to be efficacious and may actually interfere with or delay the child receiving the therapy considered to be the standard of care. It would be helpful to explain the **placebo effect** and the need for controlled studies before pursuing controversial therapies. Parents may be unaware that the observed results of a therapy may be due to their high expectations of that therapy. For example, parents strongly believing that a certain medication is effective in relieving a troubling symptom, might actually start to feel that they are observing this result even though the medication might contain nothing other than sugar (a placebo).

It would also be of benefit to explain that controlled and blinded studies look objectively at groups of affected and unaffected patients (control subjects), to determine the efficacy of that therapy. Researchers doing the study are "blinded" (do not know whether participants belong to affected or control groups). This gives researchers more objectivity in measuring the observed response to the therapy. In addition, these studies are then put through rigorous review by peers in order that the findings be published in reputable journals.

Nonetheless, if parents opt for an alternative therapy not been deemed to be harmful, it is best that the clinician remain neutral and offer support in terms of follow-up. This will strengthen the rapport between the parents and clinician and allow the

parents to determine the efficacy of the treatment on their own.

REFERENCE LIST:

Selected Articles/Books:

- Eisenberg, DM, et al. Unconventional Medicine in the United States. *N Engl. J. Med.* 1993; 328(4): 246-283.
- Spiegelblatt, N, et al. The Use of Complementary Medicine by Children. *Pediatrics.* 1994; 94: 811-814.
- Nickel, RP. Controversial Therapies for Young Children with Developmental Disabilities. *Infants Young Chil.* 1996; 8:29-40.
- Ayres, AJ. (1972). Sensory Integration and Learning Disabilities. Los Angeles: Western Publishing Company.
- Lubar, JF, et al. Evaluation of the Effectiveness of EEG Neurofeedback Training for ADHD in a Clinical Setting as Measured by Changes in T.O.V.A. Scores, Behavioral Rating and WISC-R Performance. *Biofeedback Self Regu.* 1995; 20 (1): 83-39.
- Committee on Children with Disabilities. Counseling Families Who Choose Complementary and Alternative Medicine for Their Child With Chronic Illness or Disability. *Pediatrics.* 2001; 107(3): 598-599.
- Jacobson, JW, et al. (Eds.). (2005). Controversial Therapies for Developmental Disabilities: Fad, Fashion and Science in Professional Practice. Mahwah, NJ: Erlbaum.

Websites:

American Academy of Pediatrics-Alternative Medicine site:
www.aap.org/bpi/Alternative.html

National Center for Complementary and Alternative Medicine
<http://nccam.nih.gov/nccam>

The National Institutes of Health Office of Alternative Medicine:
<http://altmed.od.nih.gov/>

The National Council for Reliable Health Information
<http://www.ncahf.org>

Autism Society of America
www.autism_society.org

National Information Center for Children and Youth with Disabilities (NICHCY)
www.nichcy.org

Zero to Three
www.zerotothree.org

The Consumer Federation of America
www.quackwatch.org