# *THE COST OF FAD TREATMENTS IN AUTISM*

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With the increase in the incidence of autism, there has been a corresponding increase in the number of treatments for this disorder. Professionals generally recognize the need for effective treatments. Effectiveness is typically considered to mean the use of quality research with good control over internal and external validity threats. Thus, only treatments that have quality research support showing effectiveness in alleviating negative symptomology of autism should be disseminated for use on a widespread basis. However, many fad treatments exist that have no such proof of effectiveness. The use of such treatments waste time and money, and prey upon the emotional vulnerability of parents and caregivers. Two such fad treatments, Sensory Integration Therapy and Relationship Development Intervention® are discussed in terms of data on effectiveness and cost of treatment.

When considering interventions for autism, there is agreement on the importance of proof that a treatment is actually effective; that is, it actually produces positive gains in skills of the person with autism. Most behavior analysts and treatment providers adhere to a standard of "effectiveness" that incorporates objective measurement using an experimental design that is implemented with adequate control over validity threats and other potential confounding variables. Thus, consumers should expect that treatment providers have some objective evidence to support claims of treatment effectiveness.

This "empirical frame of reference" for judging effectiveness is supported by many committed to autism treatment. For example, the Organization for Autism Research (2008) advocates dissemination of the current state of the "Science" in autism research. The Autism Society of America (2008) lists several guidelines, one of which is, "has the treatment been validated scientifically?" Even the federal education law requires that teachers use "scientifically-based practice" when working with children, both typical and those with special needs.

Specifically, what are criteria for valid evidence of effectiveness? An important publication addressing these criteria was the New York State Department of Health (DOH) Clinical Practice Guidelines (1999). The DOH formed a panel of professionals and parents that developed criteria for what constituted quality research evidence for treatment effectiveness. Included in these criteria were: (a) use of experimental design, (b) controls for bias, and (c) multiple studies done by multiple investigators. The guidelines exerted a major influence on the shaping of evidenced-based practice in the early intervention of autism.

In addition, Newsom and Hovanitz (2005) presented a compelling list of characteristics that would be part of any criteria. They argued that any test of treatment effectiveness must meet several standards of quality, including that: (a) terms must be operationally defined, (b) reliability of measurement must be assured, and (c) the treatment in question must be tested using experimental procedures (e.g., identification of independent and dependent variables, controlling for internal validity threats, etc.). Similar criteria were identified by Chambless, Baker, Baucom, Beutler, Calhoun, Crits-Christoph, et al. (1998) who proposed criteria that must be met by treatments used by clinical psychologist for those treatments to be considered effective. These criteria included: (a) a number of within-subject design experiments with more than nine subjects, (b) treatment manuals must exist specifying the details of the treatment methodology, (c) same effects demonstrated by at least two different researchers, and

(d) subject characteristics must be detailed. Therefore, there is substantial body of criteria for research that can be considered well controlled and whose results then can be judged to be most believable (e.g., Kasari, 2002; Green, 1996).

The importance of using effective treatment is underscored when considering the cost of caring for individuals with autism. It is likely that children who do not receive effective early intervention services will require long-term special and custodial care throughout their lives, which for 1996 was estimated to cost over $13 billion a year (FEAT, 1996). More recent studies suggest that the US spends $90 billion per year (Autism Society of America, 2008) to care for the 1.5 million children and adults with autism. This cost could skyrocket to between $200 billion and $400 billion by 2013 (The Autistic Society, 2008).

Given the enormous cost of caring for these individuals over their lifetime, efforts are being focused on effective early intervention strategies in the hopes of offsetting some of the long-term costs. Applied Behavior Analysis (ABA) has been shown to produce substantial benefits for many children with autism (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Birnbrauer & Leach, 1993; Fenske, Zalenski, Krantz, &McClannahan, 1985; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). However, a properly done, intensive ABA program is expensive to implement. Some ABA programs cost upwards of $100,000 per year. Jacobson, Mulick & Green (1998) found the average annual cost of an early intensive behavioral intervention program to be $33,000 per year with the average duration being three years.

However, the cost of intensive ABA services still is considered to be cost-effective over time. The original Lovaas study (1987) and subsequent replication studies (e.g., McEachin, et al., 1993; Sheinkopf and Siegel,1998; Eikeseth, Smith, Jahr, & Eldevik, 2002; Swallows & Graupner, 2005;) support the cost savings of early implementation of effective treatments for autism, such as ABA. For example, Chasson, Harris & Neely (2007) compared the cost associated with 18 years of special education to the costs associated with three years of Discrete Trial Training (DTT). Their results indicated that the state of Texas could save $208,500 per child over 18 years if early intensive behavioral intervention was implemented. Given the number of students receiving special education services in Texas, the projected cost savings approached over $2 billion. Further support of the cost savings of effective treatment comes from the Autism Society of America (2008), that reported the cost of lifelong care could be reduced by 2/3 with early diagnosis and intervention. Thus, the current research supports the contention that these early intervention ABA services would not only improve the quality of the lives of the children receiving services and their families, but also save the taxpayers billions of dollars. The cost savings would not only be seen in educational costs, but also in the costs associated with these children once they become adults. Effective early intervention could increase the number of children that grow up to be working, tax paying citizens.

Unfortunately, the number and range of fad treatments has grown in recent years as more children have been diagnosed with autism (e.g., Metz, Mulick, & Butter, 2005). Fad treatments are interventions that use scientific jargon, sound logical, are supported by celebrities, and are discussed in the media and on the Internet, where many parents can be exposed to them. Fad treatments, by definition, have no substantial body of research showing that they are effective in treating any aspect of autism. Thus, there is little confidence that they are effective in treating any aspect of autism.

Fad treatments are plentiful in autism. For example, actress, Playboy Playmate of the Year, author and mother of an autistic child, Jenny McCarthy appeared on the Oprah Winfrey Show on September 18th 2007 to speak about autism and her new book (2007). McCarthy told Oprah that she found that the glutin-free and casein-free (GFCF) diet and nutritional supplements reduced the effects of autism of her son. In fact, McCarthy (2007) claimed that she reversed the autism in her son by using these treatments and that only certain doctors can detoxify autistic children.

Some other examples include (but certainly are not limited to) secretin therapy, hypotherapy, vitamin therapy, and cranial-sacral therapy. Two fad treatments that are particularly troubling are Sensory Integration Therapy and Relationship Development Intervention®. We will briefly review each, explain that neither has research supporting effectiveness, and estimate the costs of using such treatments.

Children diagnosed with the Autism Spectrum Disorder (ASD) often exhibit stereotypic behaviors such as rocking, spinning, hand flapping, and excessive movements (American Psychiatric Association, 1994), at a frequency higher than children who are not diagnosed. Sensory Integration Therapy (SIT; e.g., Ayres, 1979) "… is a clinical frame of reference for the assessment and treatment of persons who have functional disorders in sensory processing" (Parham & Mailloux, 1996, p.307). Jean Ayers introduced this theory in the late 1960's. Ayers (1972) posited that human behavior is contingent on brain function; errors in brain functioning result in dysfunctional behavior or pediatric developmental problems. She later (1979) described sensory processing as a continuum or a circuit similar to a neural circuit. Stock Kranowitz (1998) proposed that a disruption of this circuitry results in sensory dysfunction. Problems associated with sensory dysfunction include sensory discrimination, perception problems, proprioception problems, tactile discrimination problems, visual perceptual problems and vestibular processing disorders (Parham & Mailloux, 1996).

Ayres (1979) and others (e.g., Huss, 1983) asserted that sensory integration techniques could be used to reduce the results of sensory dysfunction (such as self-stimulation). Grandin (1992) noted that deep pressure, part of SIT, can provide a "calming effect" for persons with ASD, since some (e.g., Hardy, 1990) believe that persons with autism display high levels of arousal. Other methods of providing sensory input include adding weight to vests and backpacks (e.g., VanderBerg, 2001) and brushing parts of the body (e.g., Stagnitti, Raison, & Ryan, 1999).

However, upon reviewing the published research on the effectiveness of SIT, one must conclude that there is a lack of experimental research supporting the effectiveness of such procedures (see Smith, Mruzek, & Mozingo, 2005, for a recent review). For example, the research that has been published has been flawed due to research design and methodological confounds (e.g., Weinberg, Ross, Wolf, & Zane, 2006; Zane, 2006). But even though SIT should be viewed as a fad therapy with no empirical support, this approach remains a popular treatment used with children with autism, with more than 80% of surveyed Occupational Therapists reporting that they use SIT regularly in their therapy (Watlin, Dietz, Kanny, & McLaughlin, 1999). There is some belief that SIT is used more than ABA (Autism Speaks, 2008).

What are some costs to a parent or school district funding SIT for a child with autism? Fees range from $30 per hour for a group session of SIT (Integrating Pathways for Children, 2008) to $100 (e.g., Healing Thresholds, 2008) and even up to $165 per hour (ABC Therapeutics Occupational Therapy Weblog, 2008; Healing Thresholds, 2008). With an average of two sessions per week that are 60 minutes in length, a family or school district would, over the course of a year, spend over 100 hours of therapeutic time and up to $16,500 on this therapy.

Relationship Development Intervention® (RDI®) is an intervention that is purportedly a parent-based treatment designed to remediate the "core deficits" of autism spectrum disorders (Gutstein, 2000; 2005). Gutstein generally describes these so-called deficits, but fails to operationally define them, and they are different from the current definition of autism (and the corresponding diagnostic criteria) as described in the Diagnostic and Skills Manual, Fourth Edition (American Psychiatric Association, 1994).

The procedures of RDI® are many. For example, Gutstein and Sheely (2002) referred to approximately 300-400 RDI® activities that focus on social skill development. With the publication of RDI® "os" (the latest version of the approach), the numbers have approximately doubled. Thus, it is difficult to know exactly how many techniques are part of the RDI® approach, and exactly how these approaches are unique when compared to other methods for treating autism.

But what isn't clear is the extent to which published research supports the effectiveness of RDI®. Only one study that approximates a research-based investigation of RDI® has been published (Gutstein, Burgess, & Montfort, 2007). In this paper, the authors claimed that RDI® was casually related to improvements in the subjects. However, an objective review of this study identifies numerous flaws in the design and methodology that results in skepticism that the RDI® procedures were solely responsible for any improvements in the children with autism (e.g., Letso & Zane, 2008). Thus, with only one published study examining RDI®, and with confidence in the results of that research confounded by numerous design and methodological confounds, RDI® must at this time be considered a fad treatment with little empirical support of effectiveness.

What is the cost of doing RDI®? Before contractually agreeing to use RDI treatment with the child, parents are recommended to attend a 4-day introductory workshop costing $2,150 (Connections Center, 2008a). An assessment of a child, using the Relationship Development Assessment, costs from between $1400 to $2300 (e.g., Colorado Training Associates, 2008; Carroll, 2008; Sheppard, 2008). In some cases, parents must enter a contractual relationship with an RDI® therapist for a minimum of six months; costing $295 per month (and another $100 per hour for travel time); parents must create and submit two video clips of their child for assessment weekly (e.g., Carroll, 2008). In some cases, it is recommended that a home or office visit be conducted every 4-6 weeks, at a cost ranging from $100-$150 per hour (e.g., Bowden, 2008). A final estimation of cost was approximately $10,000 per year (Northeast Tennessee Autism Society, 2008).

The costs above pertain only for treatment of a child with autism. There are additional costs if someone desires to become a RDI® certified trainer. This requires three, 4-day professional training workshops for a cost of $9,240 (Connections Center, 2008b).

Although the costs of SIT and RDI® is less than the average cost of an ABA intensive treatment program, it must be emphasized that the money spent of these two fad treatments should be viewed as possibly wasted, since these therapies have no research base showing effectiveness. That is, the money spent on SIT and RDI® should be assumed to have little to no positive effect on the clients served.

### *Conclusion*

The incidence of autism continues to increase and effective therapies are desperately needed. Any proposed treatment for autism needs to be shown to have a positive effect before being widely disseminated. There are several criteria that "quality" research need to meet, including operational definition of key terms, the use of reasonable experimental designs, control over internal validity threats, reliability and validity of assessment instruments, and replication of findings. Based upon these general criteria, applied behavior analysis has been shown to be an effective treatment for use with this population. Although the published data indicate that ABA services are expensive, they are also cost effective. Money spent in intensive early intervention results in less costs for supporting an individual over his or her lifetime.

Fad treatments are dangerous for several reasons. They have no database of quality research showing that they are effective in causing any positive change in any aspect of the autistic condition. These therapies waste time that these youngsters with autism do not have to waste. From all that is known about the importance of early intervention to ameliorate the defects caused by autism, time spent on unproven treatments delay the implementation of therapy that can actually make a difference. In addition, the thousands of dollars wasted on futile use of treatments with no proven track record of effectiveness could have been used to provide effective treatment.

Not only do fad treatments cost parents money, but also there is an emotional cost associated with them as well. Schopler (1999) suggested that the additional stress of raising a child with a disability leads to frustration and disappointment for the parents. Parents look for emotional support and find it sometimes in ways that are unproductive. Allik, Larsson and Smeje (2006) found that parenting children with developmental disabilities, including Pervasive Development Disorders (PDD), is associated with impaired mental health, higher levels of stress, a sense of devaluation and blame and impaired physical functioning such as tiredness or exhaustion. Dumas, Wolf, Fisman and Culligan (1991) studied parents of children with and without special needs. They found that parents of children with autism and behavior disorders experienced statistically and clinically higher levels of parenting stress as compared to the group of parents with typical children. The group of parents with disabled children also presented with higher levels of dysphoria, intense anger, guilt, depression and anxiety.

Given all the additional stress and intense emotions that these parents feel, it is no wonder they are vulnerable to the latest fads. When McCarthy (2007) proclaims there is only a limited amount of time during which treatment will help improve a child with autism, pressure is added to these parents to do as much as they can as fast as they can.

Because of this overwhelming pressure to get in as much therapy as possible while their child is young, Metz, et. al (2005) suggested that parents of children with autism are a magnet for all kinds of unsupported or disproved therapies. Many parents try multiple approaches, often doing them simultaneously, in a shotgun blast approach, hoping that one of them or a combination will cure their child. Avoidance of guilt, say Metz, et al., may play a role in this behavior of numerous therapies, as no parents wants to think they could have done more or missed the one therapy that would have changed their child. One survey suggests that the average parent of a child with autism has tried seven different therapies (Green, Pituch, Itchon, Choi, O'Reilly and Sigafoos, 2006). However, this makes it impossible to distinguish between what is working and what is not, giving the fad treatment even more fanfare.

Fad treatments provide a triple threat. They waste money that could be used in providing effective treatment. They waste precious time that a child with autism needs to be supported with therapy proven to be effective in increasing skills. However, as horrible as these facts are, the worst is the false hope that fad treatments give the concerned parents and caregivers. The families are so emotionally invested in doing anything that can help their child; they are likely to try anything. That is why treatment providers must adhere to the criteria of empirical evidence and use only methods that have proven effectiveness (Behavior Analysis Certification Board, 2008). To do anything otherwise is to increase the financial, emotional, and time burden of parents and children with autism, and to decrease the chances of the child living a life as independent as possible.

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