Integrating Biomedical and Behavioral Science: ***The Happy Future Ahead***

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Background

In general, professionals in the autism field acknowledge only a few "accepted" treatments—most notably, applied behavior analysis (ABA) and the drug Risperdal (risperidone). In contrast, parents worldwide are relying on a wide range of interventions, including biomedical treatments, to help their children. Many of these parents are reporting significant improvements in their children's quality of life as a result of these treatments.

The main reason for the division between professionals and parents is that professionals tend to rely mostly on findings from research published in peer-reviewed journals. Parents, on the other hand, learn from other parents' experiences as well as their own trial and error.

Historically speaking, two independent lines of research into the efficacy of treatments for autism—behavioral and medical—began in the early 1960s. Behavior modification, later termed applied behavior analysis (ABA), was first implemented by Carl Ferster in the early 1960s at the Indiana University Medical Center. It was soon embraced by UCLA's Ivar Lovaas, who continued and refined this line of research. Despite ABA's dramatic results, the profession accepted it as an effective treatment only after 30 years of research.

During the 1960s, medical research focused primarily on the effectiveness of various psychoactive drugs such as LSD, Haldol, Mellaril, and fenfluramine, but with very limited success. Although these drugs sometimes reduced or eliminated behavioral problems, they also retarded cognitive function and growth and decreased social interaction. Furthermore, these drugs were associated with severe side effects including Parkinson-like tremors, pulmonary hypertension, and, in some cases, death. Risperdal, a drug recently approved by the Food and Drug Administration as a treatment for autism, is also associated with many side effects including obesity, dangerous alterations in blood glucose levels, and strokes.

While the biomedical approach to the treatment of autism is receiving more and more attention, there are only a few dozen studies to date supporting its efficacy. This article will discuss the biomedical approach and demonstrate the need for objective documentation of the many treatments associated with this approach as well as the desirability of combining this approach with behavioral strategies.

The biomedical approach versus the drug approach

There are a number of biomedical approaches to the treatment of autism, including the Autism Research Institute's Defeat Autism Now! approach, the Pfeiffer Treatment Center approach, and many more. These approaches do not rely on psychoactive drugs as their primary treatment of choice. Rather, they focus on examining an individual's biochemistry and using the resulting information to design a specific therapeutic regimen to treat the person's underlying physiological, whole-body problems (Jepson, 2007). In contrast, the primary focus in the drug approach is to reduce or eliminate behavioral problems, and little consideration is given to treating the underlying biochemistry.

Since 1967, the Autism Research Institute (ARI) has surveyed parents on the efficacy of drug and biomedical treatments. More than 26,000 parents have completed the survey, and the results clearly show that

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drug treatments often do more harm than good. In contrast, treatments associated with the biomedical approach, such as specific supplements, restricted diets, and detoxifying agents, are typically rated as beneficial with few adverse effects. Some critics have discounted the survey, stating that parents are biased because they "desperately" seek to find positive effects of a treatment. However, this argument does not explain why most of the drug treatments are rated poorly—they should likewise benefit. The treatment survey can be found on ARI's website at **www.AutismTreatmentRatings.com.**

The development of the biomedical approach

The biomedical approach to the treatment of autism began to take shape in 1995 at the first international think tank on autism held in Dallas, sponsored by ARI. A group of thirty clinicians and researchers gathered at a weekend meeting and agreed to begin communicating with one another and coordinating efforts to understand and treat individuals on the autism spectrum. The group agreed that many individuals on the autism spectrum suffered from immune problems. Furthermore, for the first time, a group of professionals acknowledged the relatively high prevalence of gastrointestinal problems in this population. The group termed their approach "Defeat Autism Now!," and Drs. Bernard Rimland, Sidney Baker, and Jon Pangborn are credited with its founding.

Prior to the advent of the biomedical approach in 1995, many clinicians independently learned to treat physical and behavior symptoms by relying mostly on non-drug interventions such as vitamin and mineral supplements. A number of them also recommended restricted diets. Many of these physicians began corresponding with Dr. Rimland after reading his research studies and other writings on the use of vitamin supplements (e.g., vitamin B-6 with magnesium, dimethylglycine) and restricted diets (e.g., "caveman," gluten-free/casein-free). As a result, many of them were invited to the 1995 think tank.

Clinicians who rely on the biomedical approach often prescribe treatments that have received little or no attention in the medical literature. Interestingly, many of these clinicians "discovered" these interventions independently of one another. A good example is the finding that calcium supplements may reduce eye-poking. The finding is not surprising, as calcium deficiency is known to cause eye pain. Dr. Mary Coleman, a well-respected medical researcher, published a study showing that calcium supplements reduced eye-poking in a group of children with autism (Coleman, 1994). This study is rarely cited in the self-injury literature. However, several clinicians who are aware of the relationship between calcium deficiency and eye pain recommend calcium supplements when their clients engage in eye-poking.

ARI think tanks allow clinicians who independently develop treatments such as this to share their information and receive feedback from other clinicians who try their ideas. At these think tanks, researchers also present their latest findings. These presentations often lead to discussions on which treatments may normalize or repair problems associated with autism, such as inflammation and oxidative stress. Thus, the think tanks allow clinicians and researchers to rapidly disseminate, test, and evaluate biomedical treatments, leading to a constant refinement of treatment and research strategies.

Clinicians who integrate the biomedical approach into their practice respect the importance of peer-reviewed research. However, published articles documenting the efficacy of treatments associated with this approach have been sparse. There are several reasons for this. First, many of these pioneering clinicians are not well-versed in research design. Second, the cost of conducting such studies is usually very high. And third, it is very difficult to obtain approval from an Institutional Review Board when a study involves modifying a child's physiology. Practitioners of the biomedical approach frankly acknowledge the need for rigorous, empirical studies that carefully evaluate the many promising treatment regimens that they have developed over the years. Fortunately, federal granting agencies and private philanthropic foundations have begun to show interest in funding scientific studies that analyze the effectiveness of the biomedical approach, a development that has the potential for identifying and validating the most beneficial treatments.

Finally, the few biomedical studies published in journals and presented at conferences tend to focus primarily on physiological changes (i.e., normalization of the body's biomedical processes). Biomedical researchers often add, typically as a side note, that the participants are doing much better behaviorally, as well, and that their families see many positive changes in individual functioning. That is good; however, anecdotes are no substitute for hard data since they will never convince skeptics. Hence, we have the necessity for evaluating the broader benefits of biomedical approaches by incorporating ideas, data, and methods from the behavioral part of the field.

The behavioral approach

The biomedical approach has a potential ally to help families alleviate the suffering caused by autism: behavioral psychology. For 50 years, data have been accumulating across thousands of studies documenting the effectiveness of applied behavior analysis. ABA is based on the principles of operant conditioning, best articulated by world-renowned Harvard psychologist, B. F. Skinner. Operant conditioning explains how people learn both good things (e.g., social interaction, communication, self-help skills, and academic subjects) and bad things (e.g., aggression, self-injury, tantrums, disruptive behavior, and noncompliance). The fundamental idea is that how we behave is determined by the consequences (payoff) for our behavior. If the consequences are negative, we will do the behavior less often in the future; if they are positive, we will do it more often. This simple idea has been developed into an elaborate technology that has proven to be immensely helpful in building skills and reducing problem behavior across the entire autism spectrum (Lovaas, 2003). However, the burgeoning field of biomedical science has begun to suggest why ABA, though absolutely necessary to promote good child development, may not be sufficient.

Taken as a whole, it is fair to say that the biological setting events produced by medical conditions can greatly impact behavior, cognition (learning), affect (emotion), and quality of life. Therefore, it is time for behaviorists and biomedical practitioners to pool their knowledge for the greater good of people with autism and their loved ones.

Ignorance is not bliss: Why behaviorists need to collaborate with doctors

Consider the case of 14-year-old Timmy, who is diagnosed with autistic disorder. His teacher, behaviorally trained, decides to reward him for making progress on his reading assignment by intermittently giving him a variety of snacks such as potato chips, chocolate, and sips of soda. At first, Timmy is highly motivated by these rewards and cheerfully complies with all his teacher's requests. However, after 30 minutes of work, he becomes increasingly irritable and, out of the blue, starts punching his teacher and banging his head on the table. Horrified, but well trained in behavioral strategies, his teacher decides that Timmy has become tired and needs a rest so she prompts him to request "Break," a strategy known as functional communication training (FCT). This strategy typically causes children to stop their aggressive behaviors and make verbal requests instead (Carr & Durand, 1985). The procedure seems to work for a while but when the teacher resumes instruction, Timmy becomes violent again within 10 minutes. After repeated failures, the teacher gives up on FCT and agrees to have a psychiatrist put Timmy on risperidone, a drug often prescribed for controlling aggression. The drug fails miserably. No one at school can understand why both ABA and drug therapy were ineffective. Fortunately, Timmy's mother had been searching the ARI website and learned that children with autism often suffer from GERD (gastroesophageal reflux disease). In this condition, acid backs up from the stomach into the esophagus, producing severe and painful heartburn. Mother takes Timmy to a pediatric gastroenterologist who confirms that Timmy has GERD. The doctor puts Timmy on Nexium and, within a few days, the teacher reports that Timmy's behavior has improved dramatically and he is, once again, progressing academically.

Let us revisit the teaching situation described in light of the GERD diagnosis. Potato chips and other fried foods are great at producing stomach acid. Normally, that acid doesn't back up into the esophagus because the muscle at the top of the stomach (the lower esophageal sphincter muscle or LES) is tight and restricts reflux. However, chocolate and many sodas contain caffeine that has the effect of relaxing the LES, allowing acid reflux. The behaviorally trained teacher thought she was rewarding Timmy's good academic performance with his favorite snacks. Of course, she was, but in addition, she was unintentionally promoting GERD. As for the psychiatrist, she was, in effect, trying to control GERD with a drug, risperidone, that is totally irrelevant to GERD.

What we learn from this example is that behavioral training and procedures are not enough. Ignorance is not bliss. Ignorance is dangerous.

Behaviorists beware: Many medical conditions loom in the lives of people with autism

GERD is not, by any means, the only medical condition seen in people with autism. There is a growing scientific literature demonstrating the presence of a wide variety of gastrointestinal problems, seizures, sleep disorders, metabolic abnormalities, hormonal imbalances, infections, allergies, and immunological challenges (Bauman, 2006). These conditions not only produce symptoms of pain and discomfort but can also result in fatigue, irritability, poor concentration, hyperactivity, and anxiety. In behavioral jargon, these negative symptoms are referred to as biological setting events (Carr & Smith, 1995). A setting event (e.g., pain) can alter how a person with autism responds to a given situation by changing the valence (i.e., aversiveness) of that situation. So, when Timmy was feeling well, the academic situation was pleasant and he was eager to earn his snacks by working hard. When the snacks produced heartburn, the academic situation was intolerable (aversive) and Timmy tried to escape from it by becoming aggressive. It should be clear that the many negative, medically-driven setting events we listed will do more than just set off problem behavior. Difficulty in concentrating will prevent academic progress. Anxiety will interfere with social behavior. Fatigue may diminish communication. Multiple setting events will, over a period of time, harm subjective well-being (happiness) and make it difficult for children and their families to enjoy living together and participate meaningfully in community life. Taken as a whole, it is fair to say that the biological setting events produced by medical conditions can greatly impact behavior, cognition (learning), affect (emotion), and quality of life. Therefore, it is time for behaviorists and biomedical practitioners to pool their knowledge for the greater good of people with autism and their loved ones.

Integrating Biomedical and Behavioral Science: The Happy Future Ahead

There is a growing recognition of the many benefits of the combined efforts of biomedical and behavioral scientists and practitioners (Carr & Herbert, 2008; Granpeesheh & Dixon, 2009). Let us review two of them: diagnosis and treatment.

Diagnosis. Typically, doctors diagnose medical problems by asking the patient about their pain and discomfort. However, children with autism are poor at communication and that puts the doctor at a tremendous disadvantage in making diagnoses. Fortunately, for many years, there have been behavioral procedures available for

teaching children how to label their "feeling" states (Lovaas, 1981). For example, when a doctor sees a child who has a long history of wincing, belching, and rubbing their throat area, GERD and esophageal damage might be suspected and, if confirmed via endoscopy, the child might be prescribed Nexium. Since medication is often not 100% effective, there can be flare-ups in the future. At that point, a mother with the help of a behaviorist could be taught to prompt her child to point to his/her throat and say "hurt" when displaying symptoms. Over time, this type of repeated training typically results in skill mastery and the child spontaneously points to his/her throat and says "hurt" when experiencing pain from GERD. Now, when the child is brought to the doctor's office and asked about symptoms, he/she communicates appropriately, thereby helping the doctor. This same type of instructional procedure can be applied to help a child express the location of pain relevant to a wide variety of medical conditions with the result that the child becomes a "good patient."

Behavioral procedures can also be useful in helping doctors to get patient compliance during a physical exam. Unfortunately, the novelty and lack of predictability of the exam are often anathema to people with autism and they respond by becoming violent, thereby preventing the doctor from completing the exam and making potentially valuable diagnoses. Fortunately, the behavioral literature is replete with strategies that can be used to desensitize the patient to the exam. For example, there are techniques for building rapport, for allowing the patient more control by being able (within limits) to choose the order of examination procedures, for introducing pleasant events (e.g., music, toys, humor) that induce positive mood, for using visual schedules that enhance the predictability of the exam sequence, and for teaching useful communication skills (e.g., "I am afraid") that the doctor can respond to. When this package of procedures is used, the person with autism becomes calmer and more compliant. Indeed, in one study, the doctor's ability to finally complete an exam after many failed attempts resulted in his being able to diagnose painful sinusitis that, once treated, caused the adult patient to improve behaviorally (Carlson, 1999).

Treatment. Pain and discomfort are commonly associated with a variety of illnesses, and doctors are often able to prescribe effective medications and ancillary treatments to cure or manage these conditions. As noted previously, it is also true that, even when treated successfully, many chronic conditions flare up from time to time and result in continuing problems. Fortunately, behavioral procedures can often be combined with medical procedures to limit the negative impact of pain and discomfort (Carr & Blakeley-Smith, 2006; Carr, Smith, Giacin, Whelan, & Pancari, 2003). For example, on "sick" days, a child's schedule can be reconfigured so that it is less demanding, additional support can be provided to help deal with daily frustrations, a variety of positive activities can be introduced to reduce the aversiveness of situations and distract the child from their physical condition, and, most importantly, the child can be taught to communicate important information that elicits help from his/her caregivers (e.g., "My tummy hurts," "I feel hot," "I'm tired.").

When biomedical and behavioral treatments are combined, it is likely that one of the main effects is to eliminate the biological setting events that we described earlier. Therefore, not only is the person with autism healthier, but he/she also shows widespread improvements in other areas of functioning. For example, once illness-related difficulties in concentration are reduced, learning improves. As anxiety comes under control, the individual becomes more social. Less fatigue can be associated with more communication. As these multiple setting events are gradually eliminated over time, people with autism are described as becoming happier and better able to function in the community. The result is an improved quality of life for them and their families.

The time for integration is now

For too long, biomedical and behavioral scientists and practitioners have gone their separate ways, barely communicating with one another. Things are about to change. There is now a general recognition in the field that, by working together, we can advance our understanding, our methods of assessment and diagnosis, the effectiveness of our treatments, and our ability to produce truly meaningful and positive outcomes. Many clinicians and parent groups are more than willing to assist researchers in bringing together the biomedical and behavioral fields. A bright and exciting future lies ahead for people with autism and the many people who support them.

References

Bauman, M.L. (2006). Beyond behavior—Biomedical diagnoses in autism spectrum disorders. *Autism Advocate*, 45(5): 27-29.

Carlson, J.I. (1999). *Escape-motivated problem behavior in the medical and dental setting: A multicomponent intervention.* Unpublished doctoral dissertation, State University of New York at Stony Brook.

Carr, E.G., & Blakeley-Smith, A. (2006). Classroom intervention for illness-related problem behavior in children with developmental disabilities. *Behavior Modification*, 30, 901-924.

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis*, 18, 111-126.

Carr, E. G., & Herbert, M. R. (2008). Integrating behavioral and biomedical approaches: A marriage made in heaven. *Autism Advocate*, 50 (1), 46-52.

Carr, E.G., & Smith, C.E. (1995). Biological setting events for self-injury. *Mental Retardation and Developmental Disabilities Research Reviews*, 1, 94-98.

Carr, E.G., Smith, C.E., Giacin, T.A., Whelan, B.M., & Pancari, J. (2003). Menstrual discomfort as a biological setting event for severe problem behavior: Assessment and intervention. *American Journal on Mental Retardation*, 108, 117-133.

Coleman, M. (1994). Clinical presentations of patients with autism and hypocalcinuria. *Brain Dysfunction*, 7, 63-70.

Granpeesheh, D. & Dixon, D. (2009). Treating the whole child: An integration of biomedical and behavioral interventions. *The Autism File*, Issue 31, 119-121.

Jepson, B. (2007). *Changing the course of autism*. Boulder, CO: Sentient Publications.

Lovaas, O. I. (1981). *Teaching developmentally disabled children*. Baltimore: University Park Press.

Lovaas, O. I. (2003). *Teaching individuals with developmental delays*. Austin: Pro-Ed.