



Integrating Behavioral and Biomedical Approaches

A Marriage Made in Heaven

BY EDWARD G. CARR, PH.D., AND MARTHA R. HERBERT, M.D., PH.D.

If you are working with a person who has autism and do not use applied behavior analysis (ABA), you will not get very far. If you are working with a person who has autism and only use ABA, you will not get far enough (Carr et al. 2002). Why should this be the case? Consider a teenage boy with autism who has undiagnosed GERD (gastroesophageal reflux disease). At various times throughout the day, he experiences relentless burning in his throat, painful bloating and a foul acid taste in his mouth. During these episodes, his teacher, unaware of the GERD symptoms, continues to use ABA strategies to teach academic and social skills. These strategies, normally effective, now inexplicably set off bouts of self-injury and aggression. New ABA strategies are added to manage the behavior. These fail. Therefore, the young man is given the drug Risperidone to control the behavior. The drug also fails. When his parents are interviewed, they note that over the past year their normally cheerful and outgoing son has become increasingly moody and reclusive. He often has difficulty sustaining attention and completing tasks. He has become needier and more demanding, more disruptive of family routines. Family quality of life has sunk to a low level. Everyone agrees that his behavior seems “random”

and unconnected to his home or school environment. Desperate and fearing the worst, his parents take him to a doctor, but the boy becomes fearful and violent during the exam, refusing to cooperate. He is unable to answer any of the doctor’s questions about his health because of his poor communication skills.

Does this scenario sound familiar? For many thousands of parents, teachers and job coaches, this situation, associated with a variety of medical issues, repeats itself daily. Fortunately, new developments in the field, spearheaded by groups such as ASA and the Autism Research Institute, have culminated



in an approach called TGRI (Treatment-Guided Research Initiative), a systematic attempt to understand, assess and remediate a broad array of biomedical factors. The central theme of this paper is that the impressive potential of TGRI can be most fully realized by integrating 50 years of behavioral concepts, methods and evidence-based practices into the biomedical model.

A BRIEF HISTORY

For a long time, autism has been viewed as a developmental disorder, prenatal in origin, and resulting from genetic anomalies that produce structural or functional brain damage. Since genes cannot be fixed and brain damage cannot be undone, it makes sense to try to teach children and adults with autism as many skills as possible to help them improve their overall functioning. A powerful ABA technology exists to build these skills (Lovaas 1981), yet, as our GERD example illustrates, there may be more to autism intervention than an exclusive focus on skills training. In fact, the field is undergoing a paradigm shift from conceptualizing autism as a polygenic brain disorder to a medical disorder that affects the whole body, not just the brain (Herbert 2005). This paradigm, the driving force behind TGRI, is plausible given scientific knowledge documenting higher rates of both chronic and acute medical conditions in people with developmental disabilities as compared to the general population (Asberg 1989; Minihan 1986). Indeed, disorders related to seizures, sleep disturbances, gastrointestinal symptoms, metabolic problems, hormonal imbalances, infection, allergies and immunological challenges have all been described in the biomedical literature on ASD (Bauman 2006). The prominence of these factors has led many scientists to call for a national policy initiative in which biomedical and behavioral sciences are integrated so that the synergy between them results in more effective approaches to ASD and related disorders (Lakin & Turnbull 2005). TGRI can be responsive to this need.

HOW CAN BEHAVIORAL APPROACHES HELP?

There are five areas in which behavioral approaches can be integrated with biomedical approaches within TGRI. First, the



behavioral concept of a “setting event,” described shortly, can function as an important bridge between the biomedical and behavioral fields. Second, behavioral strategies can be useful in desensitizing people with ASD to medical examinations, thereby facilitating diagnosis. Third, behavioral intervention can be used to ensure that people with ASD adhere to prescribed treatment regimens. Fourth, single-subject methodology, a hallmark of behavioral research, can be used to assess medical problems unique to each individual, an important advantage given the

heterogeneity of medical problems in the ASD population. Fifth, behavioral intervention can be used to help people with autism and their families cope with residual pain, discomfort and other issues that may exist even after medical intervention is in effect, and promote a higher quality of life for both the person with autism and his/her family. Let us now examine these five areas in turn.

Understanding Biological Setting Events: A Bridge Concept

For decades, the biomedical and behavioral fields have been developing in parallel fashion with little communication between them. Differences in training, technical jargon, priorities and publication venues have had the effect of minimizing transfer of knowledge across fields. What we need is a “bridge concept” that helps to bring the two fields together. The notion of a “setting event” (Carr & Smith 1995; Kantor 1959) is just such a concept. In the present formulation, a setting event is any biological factor that alters an individual’s response to a given environmental context. Consider again the young boy with GERD. His physical symptoms, including pain, constitute a setting event. Normally, when he is feeling well (setting event absent) and his teacher makes certain academic demands on him, he is able to tolerate these demands even when they are somewhat frustrating. However, when he is in pain (setting event present), those same demands are experienced as highly aversive, and the boy becomes aggressive in an attempt to escape the instructional situation. In this example, the concept of pain as a setting event helps link aggression (an aspect of behavior) with gastrointestinal disturbance (an aspect of biology).

In fact, the number of potential medical factors in ASD that can produce biological setting events in the form of pain is quite large. Pain and discomfort can result from many medical conditions commonly found in people with ASD (Bauman 2006): gastrointestinal disturbances (e.g., diarrhea, constipation, GERD), seizures (producing musculoskeletal pain), dysregulated immune systems (resulting in inflammation and susceptibility to infection) and allergies. An emerging scientific literature suggests that people with serious disabilities, including ASD, likely experience pain at higher rates than the general population,

cooperation during physical examinations (Ziring et al. 1988), making meaningful diagnosis difficult. Fortunately, behavioral procedures are available to desensitize the patient to medical and dental exams, thereby increasing cooperation, decreasing anxiety and problem behavior, and facilitating the detection of illness and disease. These procedures include systematically building rapport, allowing the patient some control over the sequence of components that make up the exam, interspersing preferred activities during the exam and teaching the patient to request short breaks when needed (Carlson 1999). Of course, cooperation, by itself, may not

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but that such pain is underdiagnosed because poor communication skills make diagnosis difficult (Oberlander & Symons 2006).

Pain is not the only type of biological setting event. Poor diet, metabolic disorders and resulting tissue damage often produce nutritional deficiencies in people with ASD (Jepson 2007). These deficiencies, in turn, can produce irritability and problems in cognitive processing, two categories of setting events whose presence can disrupt learning even with the best ABA program. Likewise, sleep disorders, common in people with ASD, can result in fatigue and attention deficits, two additional categories of setting events that can limit the acquisition of critical skills in educational settings. By focusing our research efforts on identifying the classes of setting events that are likely produced by different medical factors, we are building a bridge between biology and behavior, thereby deepening our understanding of why people with ASD behave as they do. By eliminating or mitigating the problematic setting events that have been identified, we can strengthen the impact of behavioral and educational approaches whose effectiveness is often impeded by the presence of these setting events.

Facilitating Medical Diagnosis

Given the prominence of physical illness in ASD and its deleterious effects on individual functioning, the issue of accurate medical diagnosis becomes a priority. Unfortunately, people with serious disabilities often display problem behavior and a lack of

be sufficient to establish a diagnosis unless the patient is also able to respond meaningfully to the physician's questions. Since people with ASD often lack communication skills, a focus on teaching the patient to identify and describe body states is essential. Thus, in the GERD example, previously described, it would be helpful to teach the child to point to his throat and sternal area and say, "hurt." It is noteworthy that systematic programs for teaching individuals to communicate complex "feeling" states have been available in the behavioral literature for some time (Lovaas 1981). By blending the training in communication skills with desensitization strategies, we can facilitate medical diagnosis that reflects the whole-body approach to ASD.

Promoting Adherence to Treatment Regimens

Children with ASD are notorious for being finicky eaters (Raiten & Massaro 1986). Consider, again, the GERD example. After the physician has diagnosed GERD, an analysis is made of the child's eating habits. The child is found to restrict his diet mostly to Coca-Cola™, ice cream, chocolate, chicken nuggets and potato chips. The high fat content in most of these foods produces acid and the caffeine in some of these foods relaxes the lower esophageal sphincter muscle, thereby allowing acid to back up from the stomach into the esophagus (reflux). The doctor prescribes the drug Nexium to control GERD. In addition, however, the child is found to suffer from nutritional deficiencies related to poor diet.



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Therefore, treatment involves not only eliminating the harmful foods, but also replacing them with apples, broccoli, whole grains and fish, none of which promote reflux and all of which contribute to nutritional health. The child responds to the new diet with violent tantrums.

In this situation, it is possible to use behavioral procedures to promote adherence to a treatment regimen involving healthy foods (Levin & Carr 2001). First, one identifies “treats” that do not promote reflux (e.g., jelly beans, red licorice, pretzels, fat-free cookies). Then, one teaches the parent to make these treats available only under certain circumstances. Specifically, the child must first eat a small portion of a healthy food (a less preferred behavior) before being allowed to consume the treat (a more preferred behavior).

This strategy is known as the Premack principle. Over time, the child is required to eat larger and larger portions of the healthy foods before being given the treats. This strategy results in healthier eating, decreased problem behavior and reduced pain from reflux. The same strategy would also be relevant to special diets, often prescribed for people with ASD, designed to address food allergies, constipation, and vitamin and mineral deficiencies.

Documenting Success: Single-Subject Research Methodology

There is tremendous variation across people with autism with respect to types of ailments. Some individuals may have GERD, while others may have a food allergy. Still others may suffer from a vitamin deficiency. How should various treatments be evaluated so that we know which ones have merit? Traditionally, one conducts a randomized clinical trial (RCT) in which children are assigned to either a treatment (experimental) group or a placebo (control) group. Then, the results are statistically compared to see which group has a better outcome. RCTs make sense when dealing with a fairly homogenous population, which, of course, is not the case for individuals with ASD. For example, if everyone in the experimental group was treated for GERD, but only some of the children actually had GERD, then only a few of the children would show improvement and it would be concluded that treatment of GERD is not helpful. That conclusion would ultimately

harm the subgroup of children who have GERD and would benefit from its treatment. Given the heterogeneity of the ASD population, it would be better, particularly at this early stage of research, to use a methodology that evaluates success at the level of the individual rather than the group.



Behavioral research offers such a methodology in the form of single-subject research design (SSRD) (Horner, Carr, Halle, McGee, Odom, & Wolery 2005). Using the example of GERD, with SSRD one might first take baseline measures of pain behavior, problem behavior, mood, academics and social interaction. Second, a behavioral/biomedical treatment would be applied and the measures repeated. Third, the treatment would be withdrawn for a brief period of time and more measures taken. Finally, the treatment would

be reinstated and a final set of measures would be taken.

This evaluative method is known as a reversal design. If the child shows multiple improvements during treatment, and regression in the absence of treatment, then one can plausibly conclude that the treatment has value for that particular child. In this manner, ineffective treatments can be weeded out and meritorious ones validated, on a case-by-case basis. SSRD methodology is a perfect fit with the philosophy of TGRI: the need to rigorously evaluate treatment, applied at the level of the individual, which respects the heterogeneity of the ASD population. There are many variations of SSRD, but they all allow doctors, parents and others to identify meaningful treatments in spite of this heterogeneity. Once a sufficient number of SSRD demonstrations has been made in the scientific literature, there is more of a justification to gather together large numbers of children who suffer from the same medical condition and evaluate a specific treatment using an RCT to determine how generalizable the treatment is across carefully selected groups of children.

Addressing Residual Symptoms and Enhancing Quality of Life

A wide array of physical illnesses and aberrant physiological states in ASD can produce pain and discomfort that, in turn, generate high rates of problem behavior and impede psychosocial and edu-

cational development (Carr & Owen-DeSchryver 2007). Even after medical intervention, symptoms will flare up from time to time, set off problem behavior and negatively impact quality of life. Behavioral intervention can be used to deal with residual symptoms. For example, when an individual is observed to be experiencing pain, one can implement several beneficial procedures. These include: presenting highly preferred noncontingent (“free”) reinforcers to make the educational or living situation more pleasant; teaching the individual to request breaks or assistance when feeling poorly; providing greater choice of activities, thereby avoiding those that are especially difficult to perform when ill; and redistributing tasks

recognize the mutual benefits of working together to integrate concepts, methods and practices derived from their two fields. The time has arrived to systematically build this integration by exploring the many opportunities for advancing assessment, goal setting, treatment synergy and quality-of-life outcomes. The time has arrived to marry together these two bodies of knowledge to benefit people with autism and their families. It will be a marriage made in heaven.

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A wide array of physical illnesses and aberrant physiological states in ASD can produce pain and discomfort that, in turn, generate high rates of problem behavior...

and demands so that the most challenging ones occur when the individual appears to be feeling better. These strategies and others have proven to be helpful with adults and children in home and school settings (Carr & Blakeley-Smith 2006; Carr, Smith, Giacin, Whelan, & Pancari 2003).

Parents often report that when progressive medical procedures are provided to their children, it is not just physical symptoms that are alleviated. Many other positive changes occur, including reductions in problem behavior, improvements in academic performance, increased sociability, better communication, more independence and greater subjective well-being (happiness). A plausible explanation for these changes is that medical intervention eliminates or mitigates many of the setting events that impede the effectiveness of ABA programs. In other words, it is the synergy between ABA and biomedical intervention that is responsible for the most positive outcomes. Within the behavioral framework known as positive behavior support, it is possible to move beyond anecdotes and rigorously study and promote the broad changes in quality of life that accrue from the integration of biomedical and behavioral approaches (Carr 2007).

A MARRIAGE MADE IN HEAVEN

The time has arrived for biomedical and behavioral professionals to

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Needs to Begin Treatment-Guided
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*ASA thanks the director of our Treatment-Guided Research Initiative, Dr. Martha Herbert, for serving as guest editor on this issue.



MESSAGE FROM THE ASA BOARD CHAIR

In this issue, phrases such as “recovery from autism” and “helping people now,” and concepts such as “using an integrated approach” are discussed. At first read, phrases such as “recovery from autism” provide both tremendous hope and skepticism. Regardless of your visceral reaction to this term, the hope of this issue of the *Autism Advocate* is to express the urgency in treating this increasingly complex and growing disability. For years, parents have heard that there is no hope, that their child will not improve and that they should move on with their lives. Many family members and professionals have simply refused to accept this outcome. Today, families and professionals are realizing that individuals can improve and have successes. And while these outcomes may vary, we need to aggressively push for treatments that involve multiple disciplines and practices that have a sound research base. Traditionally, we have taken a piecemeal approach to treatment—the child goes to one specialist for medical treatment, another for educational treatment and so forth. Today, we are pushing for a holistic or integrated approach. Treating the entire child instead of disjointed aspects can lead to better outcomes. This will require comprehensive treatment and planning, and for the traditional walls among disciplines to crumble. And while research continues to refute or examine the potential causes of autism, children are growing into adults, parents are aging, family resources are dwindling and adults remain unemployed or underemployed. Families and individuals on the spectrum can no longer afford to wait while research catches up the realities of living with this disability. Our hope is that this issue of the *Advocate* will encourage policymakers, researchers and practitioners to work in an aggressive and collaborative fashion to help people who are living with ASD now.

CATHY PRATT, PH.D.



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