Treating the Whole Child:

AN INTEGRATION OF BIOMEDICAL AND BEHAVIORAL INTERVENTIONS

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A person spans more than one arena of life. They are more than simply their medical status, their behavior, or their intellectual functioning. Over the past decade it has become apparent that medical treatments must treat the whole person, not just a single aspect of that person. This is particularly the case in autism spectrum disorders (ASD). Nonetheless, treatments for ASD almost exclusively focus on one specific aspect of the disorder, with little thought for what else needs to be addressed.

The diagnosis of Autistic Disorder is made based upon deficits in social interaction, communication, and an emphasis on repetitive behaviors. While these are the diagnostic features of the disorder, there are a number of other frequently occurring medical problems that individuals with autism face. The most commonly reported problems are increased immune dysregulation, oxidative stress, and inflammatory bowel disease. While there is limited conclusive evidence demonstrating a causal relationship between these and ASD, it is becoming clear that many children with ASD also present with a variety of biomedical problems which are most often overlooked.

Applied Behavior Analysis (ABA) has a long history of development and scientific evaluation for the treatment of autism. ABA has been referred to under a number of different names such as Lovaas Therapy, Discrete Trial Training, Pivotal Response Training, Intensive Intervention Programs, and Early Intensive Behavioral Intervention (EIBI). While many names have been used, each of these names is either a procedure of ABA (i.e., Discrete Trial Training) or a specific research program using ABA (i.e., Lovaas Therapy). It should be noted though that ABA is not specific to autism treatments; rather, it is the application of behavioral principles to specific symptoms of autism.

The evidence supporting ABA as an effective treatment for autism is substantial (Eikeseth, 2009; Myers & Plauche Johnson, 2007; Rogers & Vismara, 2007). The scientific support for ABA has led several independent bodies to endorse ABA as a treatment for autism, including the U.S. Surgeon General (U.S. Department of Health and Human Services, 1999), the New York State Department of Health (New York State Department of Health, Early Intervention Program, 1999), and the National Academy of Sciences (National Academy of Sciences, 2001). Further, public policy changes have also occurred on the basis of this evidence, such as state-level legislation mandating medical insurance companies to cover ABA treatment (e.g., Steven's Law, Arizona House Bill 2487).

While ABA is an established treatment for autism, a consistent finding across research studies is that the rate of recovery from autism is about 35% (Reichow & Wolery, 2009). Further, the number of children meeting recovery criteria in these studies has roughly stayed the same since the first report by Lovaas over 20 years ago (Lovaas, 1987). However, this is somewhat to be expected, given the general resistance in the medical community to the idea of "recovering from autism" because it implies a change in the underlying biological causes of the disorder. Regardless of what we call it though, it happens. Recovery from autism occurs every day and our focus should be on improving these rates, not on debating the semantics of long-held ideological differences.

Biomedical interventions may be one

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solution to improving recovery rates. Because ABA is based upon learning, it follows that anything that impacts a child's ability to learn may impact progress in an ABA program. Research has shown that oxidative stress may indeed play such a role (Duffy, et al., 2008; Huang, Tiao, Tain, Chen, & Hsieh, 2008; Silva et al., 2004). For each of these medical problems, there may be a specific intervention that can remove the road block to learning.

While these medical conditions and their corresponding interventions may directly impact the brain's ability to learn, there are other, less obvious, conditions that may also affect learning. For example, insomnia has a broad impact across a number of day-to-day functions such as impaired work performance, memory difficulties, and problems with concentration (Zorick & Walsh, 2000). Further, sleep problems have been shown to be directly related to an increased severity of autism symptoms (Shreck, Mulick, & Smith, 2004). In addition, pain can also have a major impact on an individual's ability to function. Consider your own productivity at work the last time you had a significant headache. Or consider how well you would do in an intensive learning situation if you had the flu. These things may not directly impact the brain's ability to acquire and store information, but they certainly impact your ability to pay attention, interact with your environment, and learn.

Thus, there is a clear rationale for considering the possible effects of biomedical interventions in treating individuals diagnosed with autism and implications for considering the integration of medical and behavioral interventions together. While biomedical interventions may impact the foundations upon which ABA programs are implemented, no studies have evaluated the proposed benefits of biomedical interventions being added to ABA programs. Therefore, the next steps in research should focus on the experimental measurement of this hypothesis.

Evidence is still emerging regarding potential causes of autism. While genetic studies have given some promising leads, no causes have consistently been identified. This is most likely because autism is actually a group of disorders with diverse causes that show similar behavioral symptoms. Determining the various phenotypes of autism (an interaction between a person's genetic makeup and environmental factors) is receiving increased attention from researchers, but they have yet to definitively identify any specific cause of autism.

Acknowledging this limitation, it is presumed that effective biomedical interventions treat the causes of autism whereas ABA helps the child acquire skills that have either been lost (regression) or never learned. It has been suggested that one treatment without the other will not achieve optimal outcomes (Carr & Herbert, 2008). For example, imagine the analogy of a flat tire caused by a nail as you are on your way to work. You might be able to fix the tire, but you are still late for work. Getting caught up will require driving extra fast. In the same way, if children receive treatments for the causes of autism and do not receive intensive interventions to catch up, they will still be delayed. The converse is also true. If you simply ignore the nail in your tire and continue driving to work, you won't be able to drive as fast or with any degree of control or you might not be able to get to work at all. This may be the case when children are receiving only ABA programs. They are not achieving the full benefit from the treatment because they are still working against the underlying cause of the disorder to begin with.

For these reasons, further research into the causes of autism and the biomedical means to treat these causes is needed. However, a significant limitation of most biomedical interventions is a lack of scientific studies that evaluate the effectiveness of these interventions. As a result, many in the medical and behavioral community dismiss these interventions as untested. This leads us to one of the ways in which ABA can help biomedical interventions: ABA offers a method to scientifically test the effects of biomedical interventions.

A number of treatments for autism have been suggested and recent reports show a diverse array of treatments being used by caregivers (Green et al., 2006). Further, parental report on the effectiveness of these interventions varies (Goin-Kochel, Mackintosh, & Myers, In Press). Goin-Kochel and her colleagues reported that of the parents who said their child had tried the gluten-free and/or casein-free diet, about half reported improvement. Similar results were reported for chelation. Further, of those parents who reported that their child received some form of psychotropic medication to treat autism, roughly half reported some level of improvement. In regards to behavioral interventions, over 70% of parents reported their child as somewhat or dramatically improved. The studies by Green et al. and Goin-Kochel et al. are a good first start at evaluating the effectiveness of interventions for autism. However, as they note, simply reporting that a child appeared to improve is open to a number of errors. Primary among these is the well-documented placebo effect; that is, simply knowing a child is receiving a treatment will influence how you perceive the child is doing. Further, a number of things may be the cause of a change in symptoms. Unless an evaluation is done experimentally, establishing that any intervention "caused" the change is impossible.

Future Directions

Meeting the needs of individuals with ASD is a challenge that will require a response from everyone involved. Future progress will be limited without an integration of biomedical and behavior analytic approaches. To meet this goal, researchers, practitioners, and caregivers alike must all do their part.

Researchers. Over the past ten years, public attention to autism has dramatically increased. A recent study shows that from 1997 to 2006 autism research funding increased 15% per year (Singh, Illes, Lazzeroni, & Hallmayer, 2009). However, the vast majority of this funding has been allocated to basic scientific research rather than to clinical outcome research. Further, published studies have focused on genetics, neurology, and diagnosis of autism while studies on clinical treatments for autism have constituted only a small portion of the literature (Matson & LoVullo, 2009). Research in the basic science of autism is important and is directly linked with improvement in our understanding of autism, and this will ultimately lead to improved treatment and prevention. However, these gains are a long ways off as it takes years for findings in basic

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science arenas to be translated into applied treatments.

ASD is a real problem now and requires a response from the research community to provide families with answers now. A greater focus must be given to improving and refining treatments of known effectiveness such as ABA as well as evaluating complimentary or alternative medical treatments. Further, treatment studies need to move beyond evaluating treatments one at a time and begin evaluating the interaction of multiple treatments to see which treatments are effective for a given subset of children.

Parent advocacy groups have done much to support autism research and a large portion of research funding comes from nonpublic sources. The recent trend towards a greater emphasis on applied research in autism (Singh, et al., 2009) is very encouraging, and this is likely a direct result of increased parental involvement in both public policy and the funding process.

Practitioners. It has long been held that the best practice of patient care is obtained with an interdisciplinary approach. Within this format, a number of treatment providers come together to integrate their services. However, this standard of care is rarely achieved. It is not uncommon for a child with autism to receive treatment from a number of practitioners at the same time. However, it is uncommon for these practitioners to be aware of the other interventions or even to know that the child is receiving additional services. This fragmented system of care must end.

An integration of ABA and biomedical interventions is at the center of actualizing the interdisciplinary model. By integrating efforts, the strengths of both treatment approaches may be merged to yield an overall improved standard of care for the individual with autism.

Caregivers. Currently there are no studies that have evaluated the integration of ABA and biomedical interventions for ASD. Likewise, professionals have been slow to work together to merge the complimentary approaches to treating ASD. This has put the caregiver in a challenging position.

Not all proposed treatments for ASD will turn out to be helpful. Some may even harm the child. Because of the significant financial costs and potential risks involved, parents should consider a proposed treatment ineffective until there is scientific evidence to suggest otherwise. This evidence does not have to come in the form of a major randomized control trial of the treatment; instead, it can come in the form of an experimentally controlled single-subject case study. The point is that treatments must have evidence. When given the rationale for a treatment, caregivers should ask their doctor for research supporting the treatment. If there is no research available, they should insist upon conducting their own child's treatment within an experimental fashion so they can know if any changes observed are due to the new treatment or not.

There is a lot of misinformation about ASD treatments. Undoubtedly the internet has been a wonderful tool for educating caregivers and practitioners alike about ASD. However, it still remains very much the "wild west" regarding which information is disseminated, with little concern for its validity. It is the caregiver's responsibility to check the validity of the sources of their information. While undoubtedly many advances in science have originated from the individual experiences of seasoned practitioners, accepting a doctor's point of view based only upon their professional reputation is not enough when it comes to a diverse disorder such as autism.

ASD constitutes a very broad spectrum, with children who suffer from a great variety of underlying co-morbid disorders. As such, caregivers must strive to understand the specific characteristics of their child and the biomarkers that suggest which medical condition is contributing to the symptoms being exhibited.

Only through an interactive relationship among caregivers, practitioners, and researchers will these questions be answered. Enhanced collaboration will lead to advances in both our understanding of underlying phenotypes and the biomarkers that allow us to identify each child's specific needs, ultimately leading to improved treatment of the syndrome.

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