

## **When the Twain Shall Meet: Biomed and Self-Advocacy**

### **Introduction**

**By Steve Edelson, Ph.D.**

*Dr. Bernard Rimland, founder and former director of the Autism Research Institute (ARI), began his pioneering work in the area of biomedical interventions in the late 1960s and early 1970s. His main focus was on nutritional supplements and restricted diets. But historically, it wasn't until the first Defeat Autism Now! think tank in 1995—during which approximately 30 professionals and clinicians met and agreed that GI and immune problems are common in autism—that the biomedical aspects of autism began to receive widespread attention from parents and professionals.*

*Participants in the think tank agreed that they would work together to better understand and treat such problems. It is thanks to ARI's Defeat Autism Now! program, founded by Drs. Rimland, Sidney Baker, and Jon Pangborn, that this movement has gained such successful momentum since that time.*

*2010 has been a monumental year in the autism community in terms of acceptance of the existence of GI problems. In January, 26 scientists published a consensus review paper documenting the research on GI problems in autism (Pediatrics, January 2010). ARI was instrumental in all phases of this project.*

*A second landmark study on GI problems was published a few months later by the Autism Treatment Network, a program of Autism Speaks. In this study, 1,185 individuals on the autism spectrum, ages 2 to 18 years, were surveyed at 15 research and treatment centers in the U.S. and Canada. The results indicated that 45% suffered from GI problems, such as abdominal pain, constipation, or diarrhea. In addition, as their age increased, so did the likelihood of GI problems [2010 Pediatric Academic Societies Annual meeting].*

*Given the consensus review paper and the large-scale survey, there should no longer be doubt within the autism community that many individuals on the spectrum suffer from GI problems.*

*By contrast, recent research on treating GI problems has been problematic. A couple of well-publicized studies implementing GI-related treatments have actually excluded those with certain GI problems, including an NIH-funded study on the gluten-free/casein-free diet (Hyman et al., IMFAR conference, May 2010) and a study examining the efficacy of digestive enzymes (Sujeva et al., Journal of Autism and Developmental Disorders, 2010). Furthermore, most of the studies investigating the efficacy of secretin, which were published almost a decade ago, did not take into account GI problems when choosing appropriate subjects or analyzing the data.*

*Why exclude these individuals from the research? The only reason that seems plausible is that they were considered "exceptions to the rule" or "outliers," and traditional researchers chose to focus their efforts only on those individuals with autism and nothing more. Given the recent acceptance of GI problems in autism, it is time for scientists to begin studying GI-related treatments in those individuals on the autism spectrum who have GI problems.*

*Finally, much of the research and discussion on GI problems in the past has focused on children on the autism spectrum. One of ARI's new initiatives is to conduct research exploring how various biomedical treatments, such as GI treatment, might help adults on the spectrum. We are fortunate to have Dr. Valerie Paradiz write a guest editorial for the Autism Research Review International on this important topic.*

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Biomed and self-advocacy: for years, these two realms have felt like polar opposites to me. I am a parent of a twenty-year-old son with ASD, and I myself was diagnosed with Asperger syndrome seven years ago. My son and I grew up together within the autistic self-advocacy community, participating in some of its earliest organizations and events. This experience has remained a constant in my life, developing into a career in autism education. Today I support schools and agencies by training staff and teachers to assist people with autism in learning skills in advocating for their needs and preferences and in becoming more autonomous players in their own sensory and social well-being.

During the 17+ years since my son was diagnosed, the most our family ever attempted that might be deemed "biomedical" was vitamin B supplements, taken orally, when my son was in early intervention. As much as I was aware of the early vaccine debates of the 1990s that have persisted until today, I felt more attuned to and engaged in activities that self-advocates were up to. I admit I also felt critical of the biomedical community, as many self-advocates on the spectrum do.

Looking back, I see that I felt this way for several reasons. The first was the vaccine scare and how it was presented in the media, as well as in some parent sectors. Frankly, it turned me off. Whenever I tried to tune in and take perspective, the voices that represented this cause felt too shrill and in-your-face to me. The second reason had to do with articles I read about research in vaccines, published in newsletters and other non-profit publications devoted to autism. Many of these appeared to be more committed to the goal of pressing home an agenda, rather than supporting rigor and ethics in scientific inquiry. Finally, the language used to describe and promote biomed causes and interventions often seemed to disregard how the autistic person might feel about it. Unfortunately, I grew to mistrust and tune out this sector of the autism field.

Ironically, as I became more involved in self-advocacy, I began to think similar thoughts of our own community. A few years into the new millennium, and shortly after my diagnosis, I began to worry that our message as people on the spectrum had become too repetitious (something we're good at) and, in many respects, just as shrill and in-your-face as the anti-vaccine voices sounded to me. It was as if all of us were playing to the media, and its love for sensation, without remembering our larger community responsibility.

In spite of the new attention autism was receiving, I was concerned we were losing ground in our combined forward momentum, our sense of discovery and our understanding of ourselves and what we wanted, whether we were parents, people with autism, or professionals. What pained me most of all were the more private incidents I witnessed, when self-advocates with autism whom I admired for their bravery and dignity found themselves in nasty fights with a mom or dad of a child on the spectrum. In fact, it was on one particular night six years ago at a major conference sponsored by one of our leading national nonprofits that I witnessed a row between a mother (whose child was non-vocal and needed intensive supports around the clock) and a young woman with Asperger syndrome who was very independent, yet also very vulnerable. She had allergies to nearly every food item you could know. The scene was harsh, each of them ultimately denying the essential human suffering of the other. That night, I saw an unfulfilled and desperate need in both of them to feel stronger and better, and I recognized it as the two forces that were at odds within me, in my own daily experience as a parent and a person with ASD.

As much as I think anger can be the juice of change, we have been spinning in circles with our usual gripes and our usual hurts for too long, and the media have had a heyday with us. Over time, I have come to see that some parents have been hurting with a loss they haven't had the opportunity to truly come to terms with; and this, unhappily, has been the same case for many people with autism. I think our urgency to right a wrong at all costs pervades many sectors of the autism community, and in some instances, it has not served us.

Yet, as divided as the biomedical and self-advocacy communities seemed to have been in past years, I also see these two particular communities as perhaps the most vibrant and forward-looking in the field today. I have grown to understand that self-advocates have many voices. And although my own efforts within this arena are educationally based and behind the scenes when it comes to politics and the media, I am able to understand and respect our more righteous representatives who tend to dominate and yes, frustrate me very much. Likewise, although I was not a parent who saw my child lose speech overnight or become very ill after a vaccination, I have heard enough direct personal accounts from moms and dads to develop a healthy respect for their need to act.

This urgency that both groups share has a potential force to rock the world (pun intended!). I have no desire to promote a vaccine agenda, but I cannot deny the fact that countless friends and colleagues on the spectrum complain of GI issues, insomnia, agitation and anxiety. I myself have experienced these health issues my entire life, and many of us are practicing biomedical approaches without even knowing that we are, simply by avoiding foods we know make us feel bad.

The major breakthroughs that have taken place in GI study since the beginning of this year, mentioned by Steve in his introduction, make me feel that something exciting is about to happen: a coming together of the adult and biomedical communities. Imagine the power of all of us together, bearing a message that need not be shrill and manipulative, that need not resort to distortion of fact or of character, but rather becomes an expression of our mutual need to learn from one another.

I would not have arrived at this hope without having had the opportunity to understand the role of ARI in the autism community from a closer distance (not only because I married its director last month!). In the past year, I have attended ARI's conferences with tremendous interest, particularly in dietary options for adults with autism, and I have tried out various non-invasive biomedical approaches, especially probiotic supplements and a gluten-free diet. The result: I have experienced greater health and well-being both physically and emotionally. I am pleased that ARI is now directing its attention to the adult population, and as this takes place, I would like to see more self-advocates help in this endeavor by constructively informing the biomed community of our concerns, needs and aspirations as people with autism.