Interview with Dr. Joyce Elizabeth Mauk

By David Celiberti, Executive Director

I had the opportunity to interview Dr. Joyce Elizabeth Mauk, a longstanding member of our Professional Advisory Board. Dr. Mauk serves as President/CEO/Medical Director of the Child Study Center. She graduated from the University of Rochester School of Medicine in 1982. She has served as Director of the Behavioral Rehabilitation Service at Children's Seashore House in Philadelphia, Pennsylvania, which is a hospital serving children with developmental disabilities and chronic illnesses. Dr. Mauk is a neurodevelopmental pediatrician who has done extensive research on autism spectrum disorders, psychopharmacology and behavioral disorders. She is currently a member of Cook Children's Physician Network, along with many other professional and scientific societies.

Tell us about your career trajectory, and how you got involved in the care and treatment of children with autism.

In the 1980s, as a Pediatrics Resident, I was drawn to children with neurologic disorders. For a while, I considered going into child neurology, but decided on a fellowship in developmental disabilities. I have always felt that, of the organs, the brain is the most interesting and the brain in action and in development was most fascinating to me. As a Neurodevelopmental Pediatrician at Children's Seashore House and Children's Hospital of Philadelphia, I was the Medical Director of a service line focused on children with developmental disabilities and behavior disorders. Needless to say, many of those children had a diagnosis of autism. At the Agency I direct in Fort Worth, about 40% of our patients have a diagnosis of autism. Since my early heavily clinical days, my role has changed.

Can you tell us more about that shift. What is a typical day like for you now?

I now spend more time in an administrative and mentoring capacity. I balance clinical, administrative, fund-raising, and several other key roles all focused on improving the lives of children with disabilities. Sometimes that entails working with complex budgets and insurance issues, sometimes by educating my lay board, mentoring clinicians, and seeing patients. Fortunately, each day is a little different.

You have been a valuable member of our Professional Advisory Board for many years. How did you get first involved in ASAT?

I was made aware of ASAT by my colleagues in the Behavior Analysis field, and enjoyed receiving the newsletters. Dr. Sigrid Glenn from the University of North Texas nominated me to join the Advisory Board during ASAT's first few years.

As you know, there has been a proliferation of so called "treatments" for autism. What pseudoscientific treatment trends concern you the most and why?

I continue to be concerned about the low level of health and scientific literacy in the general population. As a Neurodevelopmental Pediatrician, I often need to counsel families about unscientific and even dangerous treatments. Two types of treatments are most concerning to me for different reasons. Sensory Integration Therapy- generally performed by an Occupational Therapist. My major concerns about this form of treatment are the expenditures in cost and time, given that there is no scientific evidence of efficacy. Since it is performed by an accepted type of licensed therapist, it has grown and prospered to the point of being considered standard of care. In addition, it also appears to be continued for years because clear outcome measures are not established for each case. Physicians are not always knowledgeable to challenge the ongoing therapy and thus continue to authorize it. The costs to society for this treatment, which is often covered by insurance and Medicaid yet is unproven, is astronomical. Furthermore, time spent with this form of therapy is time not being spent engaged in scientifically validated treatment. "Biomedical treatments" are concerning due to potentially dangerous side effects as well as cost. Some marketing of questionable treatments include statements that the treatment is good for arthritis, heart disease, cancer, lung

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problems, and autism- or some other combinations of disorders with no common pathophysiologic process. Some physicians who claim to specialize in autism have no training in developmental disorders or psychopharmacology. For example, families should be very cautious about an ENT (ears, nose, and throat) or allergist who claims to be an autism expert. Again, I am also concerned about lost opportunity to pursue effective treatments. Psychopharmacology of behavior disorders has improved greatly and medications may play a significant role in maximizing outcome. Legitimate biomedical vs. unproven treatments are difficult for the lay person to differentiate. Unconventional, unproven medications, and "natural" treatments often have side effects and may prevent families from seeking appropriate care.

In light of plethora or treatments for autism, most of which lack scientific merit. What advice do you have for parents of newly diagnosed children?

I tell them to visit the ASAT website and also Quackwatch before starting new therapies. I tell them that helping their child will be hard work and that there is no magic involved. Also that a diagnosis of does not mean that challenging behavior should be tolerated. It is true that communication deficits may predispose a child to use nonverbal ways to communicate, but aggression or disruptive behavior should never be acceptable. I am amazed at what sometimes is accepted as an inevitable consequence of a disability- with the whole family dancing around the child's problem behavior and the behavior become more entrenched over time

What do you see as the most promising area of biomedical research?

I think a greater understanding of the genetics of autism is very promising. Current microarray technology has increased the number of children with known genetic causes- hopefully in the next ten years the clinical outcome of children with varying genetic causes will be clearer. This may help lead to improved ability to predict outcome or treatment response.

Tell us about the research you have conducted, involving children with autism.

In the past I have been involved in a research project to try and differentiate subtypes of self-injury in patients with autism and then prescribe tailored

Dr. Mauk Photo by Jill Johnson

treatments. This approach combined a functional analysis of behavior with observations on the rate, topography and associated behaviors of the self-injury. The take home message was that the majority of the self-injury was operant or learned. Of the patients whose self-injury was not operant or was mixed (had no clear antecedents or consequences, was self-maintained) some associated features such as crying, agitation, and aggression were predictive of response to medication classes (e.g., antipsychotics, SSRI's, beta blockers, and naltrexone).

Do you think the changes to the DSM-5 autism diagnostic criteria will change the diagnostic profile of the patients you treat?

For me, as an experienced clinician, the changes are largely academic. From a functional standpoint my patients need help of various intensities no matter what their disorder is called. From a practitioner in the field's point of view autism has been over identified in the last few years so there is apt to be some correction in numbers. There is also some evidence of diagnostic substitution- individuals with cognitive disability being labeled with autism, for example. An individualized approach to treatment that incorporate behavioral excesses, deficits, and the family's needs should transcend diagnosis.

I want to thank you, Dr. Mauk, for taking time from your busy schedule to participate in this interview. Furthermore, on behalf of the Association for Science in Autism Treatment, I would like you to know that your service on our Professional Advisory Board is much appreciated!