



Newsletter

Volume 2, Number 3, June 2013



Calendar of Events

June 10, 2013 -- Citizens' Advisory Committee For Special Education Meeting, 7-8:30 p.m. at the Board of Education Building, Leonardtown.

June 15, 2013 -- Smithsonian Institution Morning at the Museum at the National Museum of American History, 9:00 am—11:00 am (public hours begin at 10:00 am). Morning at the Museum is a project of the Smithsonian Institution's Accessibility Program and the Smithsonian Museums. Guided by a Community Advisory Committee comprised of museum educators, exhibit designers, professionals who work with children with cognitive disabilities, parents, and self-advocates, the Smithsonian has developed a program that includes early admission and pre-visit materials designed to help children with cognitive disabilities and their families enjoy a visit to the Smithsonian Museums. RSVP to: access@si.edu or 202-633-2921. Pre-visit materials available at: <http://www.si.edu/Accessibility/MATM>. Future Morning at the Museum events include October 5, 2013 at the National Postal Museum.

June 19, 2013 -- Autism Spectrum Support Group Meeting, 6:30-8:00 p.m. at the Coffee Quarter, California, MD.

June 19, 2013 -- Autism Spectrum Support Group Meeting, 6:30-8:00 p.m. at Panera in La Plata, MD.

June 29, 2013 -- The Smithsonian Institution presents: Morning at the Mall -- an event designed to introduce children with cognitive and sensory processing disabilities to the Annual Smithsonian Folklife Festival! Families that pre-register can access the Festival early and experience some of the sights and sounds without the crowds. Time: 10:00 am - 12:00 pm. (Festival opens to the public at 11:00 am.) RSVP: access@si.edu or 202-633-2921. Festival website: <http://www.festival.si.edu/> For additional information contact: access@si.edu or 202-633-2921 <http://www.si.edu/accessibility> Pre-Visit materials will be available at: <http://www.si.edu/Accessibility/MATM> Due to the nature of the Festival we will not have the pre-visit material available until the week of the event. All registered families will be notified when the materials are available.

Date/Location To Be Determined -- *The Autism Spectrum Support Group of Southern Maryland* will host a **Round Table Discussion** for parents/caregivers of people with ASDs to talk about educational services for children with ASDs in Southern Maryland and to identify pathways for offering appreciation for what is working as well as for addressing problem areas.





Editorial



Across the country and here in Southern Maryland, parents of children with ASDs fight for school services for their children, fight not because school personnel are inherently combative or mean-spirited, but for reasons often unfathomable to parents.

It starts with the diagnosis. In the school setting, it's an educational label. Whether parents enter the Individualized Education Plan (IEP) process armed with a medical diagnosis for their child or not, schools are required to perform their own evaluations to determine if a child is eligible for special education and related services under an IEP. That in and of itself is not a problem. What is alarming is the number of parents reporting that, regardless of the medical diagnosis, school teams in all three Southern Maryland counties are telling parents that their children with ASDs *do not have ASDs* according to schools' evaluations.

Eligibility for special education and related services is a three-pronged approach: The child must have a disability, that disability must have an adverse impact on his/her educational performance, and that adverse impact requires direct instruction. Families are frequently told when they provide privately obtained evaluations identifying their child as having an ASD that it is a "medical diagnosis" and not an "educational diagnosis," yet to negate the medical diagnosis based upon their own evaluations is inappropriate and beyond the scope of school employee duties.

While some children already receiving services under IEPs may continue to receive special education and related services upon re-evaluation, others are deemed to no longer qualify for services and may be moved to 504 Plans -- accommodations governed by Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, not by IDEA. Children newly diagnosed may be denied an IEP outright and may or may not be offered a 504 Plan, for a variety of reasons.

What is the difference between an IEP under IDEA and a 504 Plan? The National Center for Learning Disabilities defines services under IDEA as "[providing] individual supplemental educational services and supports in addition to what is provided to students in the general curriculum to ensure that the child has access to and benefits from the general curriculum. This is provided free of charge to the parent." They define services under Section 504 as "[requiring] schools to eliminate barriers that would prevent the student from participating fully in the programs and services offered in the general curriculum." To illustrate the point, 504 gives a child access to the library; IDEA gives them access to the library *and* ensures that they can read what's there.

What happens after denial of the educational label of autism? School teams are left to manage as best they can, without truly knowing the learner because that part of him/her has been denied in the educational setting. Though "good teaching" includes differentiating instruction, it's not a skill that comes easily, requiring additional training and knowledge of the learner and his/her learning needs. In the end, though, it is the children who pay the price of not having their needs met, of being labeled not *autistic* but *weird* or *unmotivated*, of being tormented and bullied, of not being helped to reach their potential.

Based on parent reports, the number of children with ASDs being denied services under IDEA has grown in our region in the past several years until the problem seems to be pervasive and is in stark contrast with the findings of MSDE's own Autism Task Force Memo and Report,

which emphasizes that “in treatment of autism early is essential and more is better.”

Regardless of educational label, children have the civil right to a free and appropriate public education. The Congressional findings of the reauthorization of Section 504 of the Rehabilitation Act of 1973 states, in part, that “...individuals with disabilities constitute one of the most disadvantaged groups in society” and that “disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society...” Research statistics show that children with unmet educational needs become adults who can't participate in society, and *that* is a disservice to children, to families, and to the community.

The Autism Spectrum Support Group of Southern Maryland is planning a round-table discussion for members (date and location to be determined) to talk about educational services for children with ASDs in Southern Maryland and to identify pathways for offering appreciation for what is working as well as for addressing problem areas. We encourage parents of children across the spectrum of services and ages to participate in the discussion, to share your child's educational story (the good and the bad) in any area, not just evaluations, and to work together as a group to create positive solutions.

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... **Alex and Zach** who helped complete the paver patio! We couldn't have done it without them! They were able to assist with the layout, seeing the puzzle that mom and dad didn't always see!

... **Joshua** for taking on the responsibility of raising the flags at Spring Ridge Middle School each morning this year. He received training on flag raising procedures, including when to fly flags at half staff, and was recognized by his principal for displaying good citizenship and responsibility.

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Features

[The Autism Spectrum Support Group of Southern Maryland](#) supports families by offering scholarships to attend conferences or workshops related to autism or similar disabilities. All we ask in return is that you provide a brief summary of your experience either in writing or in person at a Support Group meeting. Contact Terri (terri@autismsupport-somd.org) or Tracie (tracie@autismsupport-somd.org) for more information.

The following is Part 2 of a summary of the US Autism & Asperger Association 2012 World Conference in Denver, Colorado, September 6-9, 2012, by Toni Sieg. Additional articles will appear in later Newsletters.



**US Autism & Asperger
Association 2012 World Conference in
Denver, Colorado (Part 2)
by Toni Sieg**



I attended the US Autism & Asperger Association 2012 World Conference in Denver, Colorado, September 6-9, 2012. Fortunately, I was able to attend with my husband and both of my children, Alex and Zach. Alex and Zach are identical twins, 21 years old now and both on the spectrum, with a diagnosis of Asperger Syndrome. This multi-day conference was partially funded by the Autism Spectrum Support Group of Southern Maryland. I have hours of conference notes and hope to share this information with the Support Group over the next several months. This month I will focus on the second full day of the conference.

Saturday morning we started with the keynote address by Temple Grandin, Ph.D. While I have been fascinated with Dr. Grandin after I saw her movie on HBO a couple of years ago, I can now say I am even more interested in her. She is wonderful to listen to and holds so much insight. I will write more on her presentation in an upcoming newsletter. Alex had to have her autograph, so we had an opportunity to meet Dr. Grandin and speak with her one-on-one. She is the author of several books, a couple we purchased at the event: *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism* as well as *Different ... Not Less*. Both have wonderful information.



Following the keynote address, we attended “Functional Imaging of the Brain: You’ll Never See Autism the Same Way Again” by Dr. J. Michael Uszler, MD. Dr. Uszler spoke about autism not being a psychiatric disorder but an actual brain cell function disorder. He shared several brain SPECT scans and discussed how the parts of the brain work in individuals with autism. This was very technical, but fascinating.

The next session was “Grateful for the Diagnosis of Asperger’s Syndrome: It Explained Everything” by Professor Tim Page. At the age of 45, he was diagnosed with Asperger Syndrome, and he realized he was not alone. The diagnosis explained his difficulty with peers and his computer-like retention, as well as his need for routine and repetition. He discussed learning to use his “weaknesses” as strengths.

Next on our agenda, “Effects of Toxic Drugs and Chemicals on the Incidence and Severity of Autism” by Dr. William Shaw, Ph.D., was an interesting topic for the afternoon. Dr. Shaw focused his discussion on the wide

range of chemicals like mercury, lead, solvents, and organophosphates that have been implicated as risk factors for autism.

The next session I attended was by Dr. James Partington, Ph.D., BCBA, titled “Assessing and Teaching Functional Living Skills to Individuals of All Ages Using AFLS.” AFLS, the Assessment of Functional Living Skills, is a review of 735 skills in 24 functional areas, like traveling in the community, making purchases, seeking assistance as required, preparing meals, participating in household chores, and in social and leisure activities. I found this program to be very interesting. It seems to have something for a multitude of individuals, on varying ability levels and ages. I have more information on this assessment, and will be sharing more in the months to come.

While I was in the Functional Living Skills presentation, my husband and sons attended “Social Networking: 10 Lessons Learned from 25,000 Parents” by Eric Peacock, MBA. Mr. Peacock is the co-founder of “myautismteam.com”, a social networking site specifically designed for parents with children on the autism spectrum. I have been a member for a couple of years, and while I was transitioning between sessions, I had posted a picture of Temple Grandin during her presentation that morning. My husband sent me a text letting me know that they had put my post on the screen during the presentation. If you have a chance, check out www.myautismteam.com; it is a nice place to list kudos and struggles and have other parents understand.



We then attended two more sessions at the same time. I attended, “The Continuums of Autism: Cognition, Sensory Processing and Behavior” by Marlo Payne Thurman, MS. The topic focused on the differing cognitive skills, learning styles, and sensory needs of those with autism. One point was that since autism is so complex, there is often a failure to recognize the continuums of autism and instead focus on the easily observed behaviors. Ms. Thurman discussed in detail the complex relationship between cognitive processing and sensory regulation, providing insight and recommendations to address the mechanisms that negatively impact learning, social and emotional functioning, and behavior in those with ASD. While the following is from November 2011, this youtube video is the presentation Ms. Thurman gave at the USAAA conference in September 2012: http://www.youtube.com/watch?feature=player_embedded&v=UTH-OhDZDrA.

The session my family attended was “Visual Social Thinking Strategies” by Michael McManmon, Ed.D., and Sandra Wise, Ph.D. While many individuals with ASD think visually, not all do. The session focused on bringing together social thinking and visual thinking as a teaching method. One of the keys to changing the perception of the autism and Asperger diagnosis is for the individual with autism to put equal time and energy into learning about non-verbal language and social competencies that they put into their special interests.

We finished the day with the Bullying Panel.” Many of the participated in on Saturday interesting to hear their the questions from the



“Advocacy and Combating speakers from the sessions we were on the panel. It was personal accounts and respond to audience.

We did not stay for the Sunday half-day session. Our brains were full and we had a lot of information to begin to digest.

The 2013 US Autism & Asperger Association Conference will be held in Salt Lake City, Utah this August.



Bios for some of the speakers we heard during the conference (from the USAAA website):

Temple Grandin, Ph.D. (KEYNOTE) -- Dr. Grandin is one of the most accomplished and well-known adults with autism in the world. Dr. Grandin's fascinating life was brought to the screen in 2010 in the HBO production full-length film, *Temple Grandin*, which claimed seven Emmy Awards, including outstanding made-for-TV movie. She has been featured on NPR (National Public Radio), major television programs such as the BBC special "The Woman Who Thinks Like a Cow," ABC's *Primetime Live*, *The Today Show*, *Larry King Live*, *48 Hours* and *20/20*, and has been written about in many national publications, including *Time*, *People*, *Forbes*, *U.S. News and World Report*, and *The New York Times*. This will be Dr. Grandin's fourth USAAA appearance.

Dr. Grandin didn't talk until she was three-and-a-half years old, communicating her frustration instead by screaming, peeping, and humming. In 1950, she was diagnosed with autism, and her parents were told she should be institutionalized.

Lawrence P. Kaplan, Ph.D. -- Dr. Kaplan is a parent of child affected by autism. He is the Founder and Chairman of US Autism & Asperger Association (USAAA). Dr. Kaplan was the chief investigator for the first study on early diagnosis of ASD. He is the author of *Diagnosis Autism: Now What? 10 Steps to Improve Treatment Outcomes: A Parent-Physician Team Approach*. He is editor of the highly acclaimed *USAAA Weekly News*, editor of multiple USAAA Conference Proceedings Manuals, and a contributor to other autism publications. Dr. Kaplan spent the first decade of his post-graduate studies in professional and collegiate sports. He has spent the last 21 years improving the quality of life of individuals and others affected by Autism, Asperger Syndrome, and Pervasive Developmental Disorders.

Michael P. McManmon, Ed.D. -- Dr. McManmon grew up the youngest son in a family of nine children.

He is the father of six children and has nine grandchildren. He received his BA in English from Mt. St. Mary's College in Maryland and went on to complete his Master's in Counseling from Shippensburg University. He obtained his Doctorate in Special Education from the University of Nevada. Subsequently, he was licensed as a Psychologist by the State of Massachusetts. He worked for state, private, and non-profit organizations in several states prior to founding The Berkshire Center in 1984.

During his 35 years of experience with students with learning differences and Asperger's syndrome, Dr. McManmon has worked on Curriculum Development, Staff Training, Program Evaluation, and Administering Community-Based Programming. Dr. McManmon's program philosophy is to provide a loving and trusting environment in which personal growth can occur. He is the author of *Made for Good Purpose: What Every Parent Needs to Know to Help Their Adolescent with Asperger's, High Functioning Autism or a Learning Difference Become an Independent Adult*. Dr. McManmon serves on the US Autism & Asperger Association Advisory Board.

Tim Page, DFA -- Mr. Page was diagnosed with Asperger Syndrome at the age of 45 and says, "I am very grateful to have the diagnosis [of Asperger Syndrome] because it explains a lot." He is a professor at both the Thornton School of Music and the Annenberg School for Communication and Journalism at the University of Southern California. Page won the Pulitzer Prize for Criticism in 1997 for his writings about music in *The Washington Post*, where he held the position of chief classical music critic since 1995. Prior to coming to the Post, he served as the chief music critic for *Newsday* and as a music and cultural writer for *The New York Times*. During his years in New York, he was the host of an afternoon program on WNYC-FM that broadcast interviews with hundreds of composers and musicians. Page has produced concerts at venues ranging from

Carnegie Hall to New York's once-infamous Mudd Club. From 1999 to 2001, he was the artistic advisor and creative chair for the St. Louis Symphony Orchestra.

His books include, *The Glenn Gould Reader* (Alfred A. Knopf, 1984), *Selected Letters of Virgil Thomson* (Summit, 1988), *William Kapell: A Documentary Life History of the American Pianist* (IPAM, 1992), *Music From The Road: Views and Reviews 1978 - 1992*, an anthology of previously published work (Oxford University Press, 1992), *The Unknown Sigrid Undset* (Steerforth, 2001), and *Tim Page on Music* (Amadeus Press, 2002). He is the author of *Parallel Play*, an autobiographical account of "Growing up with Undiagnosed Asperger's." Page serves on the US Autism & Asperger Association Advisory Board.

James W. Partington, PhD, BCBA -- Dr. Partington is the director of Behavior Analysts, Inc., and provides services to children and their families at the STARS Clinic in Walnut Creek, California. He is a licensed psychologist and a board certified behavior analyst, doctoral level (BCBA-D), and has more than 35 years experience working with children with developmental disabilities. His expertise is in language-based intervention with children who are experiencing language delays as a result of autism and other related developmental disorders. Dr. Partington has been a faculty member of several universities, including West Virginia University, University of San Francisco, and St. Mary's College.

Dr. Partington has co-authored with Dr. Mark L. Sundberg the book, *Teaching Language to Children with Autism or Other Developmental Disabilities*. He is the author of *The Assessment of Language and Learning Skills-Revised (The ABLLS™-R): An*

Assessment, Curriculum Guide and Skills Tracking System for Children with Autism or Other Developmental Disabilities. Dr. Partington serves on the US Autism & Asperger Association Advisory Board.

Marlo Payne Thurman, MS -- Ms. Thurman is a school psychologist and a national education consultant who obtained her Specialist Master's degree from the University of Utah. Ms. Thurman started her work with special needs children in 1986. Early in her career, she developed a special interest in the unique needs of those individuals who were both highly intelligent and asynchronously developed. She specializes in assessment, advocacy, cognitive training, sensory and behavior support, and socio-emotional coaching. In 1999, Ms. Thurman founded the Brideun Learning Communities and built the Brideun School for Exceptional Children, a play-based, therapeutic school. She later founded 2E Consulting Services, which is an expansion of her private consulting services.

J. Michael Uszler, MD -- Dr. Uszler is Medical Director of the Nuclear Medicine Department at Saint John's Health Center in Santa Monica, California, Assistant Clinical Professor of Molecular and Medical Pharmacology at UCLA, and Medical Director of DrSpectScan.com. He received his medical degree from the Medical College of Wisconsin (previously known as Marquette University School of Medicine) and his master's degree in medical physics from UCLA as part of his academic fellowship in Nuclear Medicine. As a board certified Nuclear Medicine physician, he has three decades of academic and clinical experience in hospital-based care, including eight years at UCLA-Harbor General Hospital and 20 years as Medical Director of Nuclear Medicine at Santa Monica Hospital.

<http://www.usautism.org/>

