

The ALL ABOARD NEWS



A Quarterly Publication from the Advisory Board on Autism and Related Disorders

Volume XIV— Issue 4

Fall 2010

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SAVE THE DATE!

ABOARD presents our 2nd Integrative Biomedical Treatment Options For Children and Adults with Autism Spectrum Disorders

Saturday, March 19, 2011
Holiday Inn Pittsburgh Airport

Gut Biology, Pathology, and Treatment Strategies in Patients With Autism Spectrum Disorders - Anju Usman, MD

Patients diagnosed with autism have co-morbid medical conditions including gastrointestinal dysfunction. The most common issues that present are malabsorption, maldigestion, motility disorders, dysbiosis, and allergy/inflammation. This lecture will discuss gastrointestinal pathology, histology and treatment strategies for individuals on the autism spectrum as well as focus on the gut-brain-immune connection as it relates to autoimmunity and potentially PANDAS.

Autism and the Autonomic Nervous System - Anju Usman, MD

Patients with autism are in a state of chronic stress. This stress causes a particular arm of the autonomic nervous system to be turned on or activated. When chronically turned on the sympathetic nervous system can cause symptoms such as hyperactivity, anxiety, attention and focus difficulties. A chronic fight or flight response to stress can also lead to medical issues such as impaired gastrointestinal motility, immune dysregulation, and hormonal imbalances. These issues can be identified and addressed with proper testing, good nutrition, targeted nutraceuticals, and adaptogenic herbs.

Raising a Healthy Child in a Toxic World - Suruchi Chandra, MD

With the rise of environmental toxins, there has been an increased incidence of children experiencing health challenges such as allergies, digestive problems, difficulty focusing and delayed development. We will begin with a brief overview of the scientific literature of the effects of various toxins on health, including BPA, phthalates, flame retardants and toxins in our food supply. Then, tools and strategies will be presented to help you to eat well and create a healthy home that will allow your child and entire family to achieve true health. Finally, we will look at ways to help support the body's detoxification systems in eliminating the everyday toxins that we are all exposed to.

ABOARD's Saturday Seminar : "LANGUAGE SKILLS AND AUTISM"

Challenges for Teachers, Parents and Therapists.
Presented by Kathleen R. Helfrich-Miller, Ph.D.
Saturday, November 6, 2010 - 9 a.m. - 3 p.m.

The ABOARD Office, 35 Wilson Street, Suite 100, Pittsburgh, PA 15223
Call 412-781-4116 for more information or go to www.ABOARD.org !

Chairman's Message

Dear Friends,

While talking to people about autism in my role as Chairman and as a parent, I've been amazed at the varied perceptions people have of the organization. Here's a quick look at ABOARD.

Our mission is to help those on the spectrum maximize their potential and abilities in social, educational, and vocational environments. We want effected families to have accurate and timely information about autism and treatments. Through our 63 parent support groups in 48 counties, they receive emotional and practical support from other families. ABOARD has been successful for 15 years because we are made up of a community of families helping families.

Our staff consists of 3 wonderful and dedicated moms, who work half-time. Marie, Jen, and Rebecca are responsible for all that we accomplish daily. Much of the effort of our volunteers goes to raising funds to continue to provide and expand services.

Our most common contact is with the newly diagnosed family. The shock of the diagnosis and the fear and feelings of being overwhelmed are staggering. A call to ABOARD has you in touch with someone who has been through it, understands what you are going through, and knows what needs to be done next.

Our relationship with the family often spans many years with intermittent contacts. Families start on the path and do well for awhile, then, a detour occurs. Again, they often call ABOARD to ask what to do and how to get the resources for this new path in the journey.

Our conferences try to address the latest topics and trends in the autism spectrum and are geared for professionals and families. We have been providing these helpful conferences for 12 years and also offer short seminars in our office on weekends. You can read about upcoming events in this newsletter.

Our Family Support Coordinator can help if you need to relocate your family in Pennsylvania and want to arrange for services in a new area. We provide information about parent support groups, area agencies, and educational rights. We also provide welcome packets containing valuable guides and information.

Our services to families are free. Only conferences and some seminars have fees. We rely on support from donations, fundraisers, grants, and designated employee contributions through the United Way (#9817).

I hope your fall is pleasant!

Elliot Frank, Chairman, Board of Directors

A Special Thanks to our Supporters!

Special Thank you to:

Princess Lanes Inc. Pittsburgh, PA for fundraising activities held at their annual fireworks event in June to benefit ABOARD.

Thank you to Hillman Appliance Distributors, Inc. for making ABOARD the benefiting charity for funds raised at their annual customer appreciation golf outing.

In 2009 ABOARD responded to over 3,700 information requests for guidance and support, gave support to 53 family support groups, distributed 1400 information packets and 750 publications from our lending library, and provided trainings to parents, paraprofessionals, and educators. It's a massive task made possible only by the considerable help of our neighbors!

SAVE THE DATE CAMP FAIR 2011

ABOARD's 7th Annual All Abilities Camp Fair



**Saturday, January 22, 2011
10:00 am – 3:00 pm
Shoppes at NORTHWAY, North Hills
Pittsburgh, PA 15237**

MORE INFORMATION TO COME SOON!

ABOARD AND VENTURE OUTDOORS

This summer, ABOARD had the opportunity to join forces with Venture Outdoors, to provide our families some fun and free outdoor activities.



Three free Family Outdoor Festivals were held throughout the Pittsburgh region. Kayaking, biking, rock climbing, geocaching were activities available to try. Also, many vendors were on hand to talk about the educational opportunities they offered for learning about the outdoors and our environment..

Along with the Family Outdoors Festivals, ABOARD took part in three events: Kayaking Lake Elizabeth at Allegheny Commons, Family Geocaching at South Park and Family Fishing Derby North Shore Riverfront Park.

ABOARD's adult and teen social group both spent an evening learning how to Kayak and taking a test paddle at Lake Elizabeth. This was a great way to socialize and try a new outdoor activity.

As we continue our partnership with Venture Outdoors, we plan to host more outdoor events for kids, adults, and families . We would love to hear your suggestions.

These events are a great opportunity to volunteer for ABOARD. If you love the great outdoors and want to help with this project, let us know. If you are a BSC, TSS or care aid

and want to offer your experience and service to the team, ABOARD and Venture Outdoors will gladly help you get the training and skills required.

Venture Outdoors has many activities for all ages and skill levels. We are happy to announce that VO is offering a discounted family membership to ABOARD families. See below for more information about how to take advantage of this offer!



As an ABOARD Family, you have the opportunity to join Venture Outdoors at a 20% discount on the regular membership fee. Your \$40 (includes discount) VO Family Membership fee covers up to 6 people for an entire year so when you sign up include your TSS or Care Aid so they can assist you on the events you choose. (You will be able to update this list as TSS or Care Aids change). In order to take advantage of this offer, you must register your membership with Venture Outdoors on-line:

Log onto www.ventureoutdoors.org

- Sign up for a membership and at the *check out* it will ask you for a *gift certificate or promo code* Use the following promo code to your new membership, Make sure you click **"Update Totals"**

ABOARDmem – 20% Discount on Membership - \$40 for a family membership (covers 6 people)

Membership Benefits

- Discounts on Venture Outdoors trips and activities, including \$5 off per hour on any rental at Kayak Pittsburgh
- Invitation to members-only events and free member events!
- Venture Outdoors high-durability bumper sticker and variety of merchant discounts.
- Subscription to E-news and the Venture Outdoors newsletter

Thank you for joining the outdoor community! Your membership card(s) will be sent to your address within the next few weeks. If you do not receive it, please contact the Venture Outdoors Membership office at 412-255-0564 ex.28.

We also recommend you contact the Venture Outdoor office when you register for an event so the trip leader can get to know you and your family for any special circumstances or needs you might have!

Ride to the River for Autism Wrap Up



On August 8th the first ever Ride to the River for Autism Poker Run to benefit ABOARD took place at Three Rivers Harley Davidson in Glenshaw, PA. The day was sunny and filled with great people that came together for a great cause! We even had a mom pull up on her hot red scooter and her son with Autism on back of Dad's Harley to enjoy the ride that day.

"As a member of a six motorcycle family, I was so excited to see that ABOARD was having a benefit "Ride to the River". Our son was diagnosed with PDD-NOS 12 years ago and I have called ABOARD on numerous occasions for answers and support. I was happy to be able to return the favor by supporting them! Our son enjoys riding on his dad's motorcycle and his twin brother joined me on my scooter...so it was the perfect family activity. I have to admit that when I first arrived on my little red scooter I was intimidated by the sea of Harleys in the parking lot. But the

day was beautiful, the ride was enjoyable and the people were wonderful! It was a great experience that my family and I would definitely do again."

- Maria O'Connor



The day started off with a poker run rider leaving at 11:00 and stopping at three spots before returning for an afternoon of entertainment. The entertainment started off with the Flying Sock Monkeys a band of young inspiring musicians with autism getting to sing and play along with several band members

from the two other bands playing that day Blues Junkies and Jumpin Jack Flash!

The event was catered and the auction items were in hot demand as the day rocked on!

ABOARD is thankful for all the support we received that day:

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Ride to the River for Autism Wrap Up

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 Lisa Bill
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 Sandie and Jesse Denning
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 Dina Gaborko
 Kim Hoff
 Darla Horn
 Allison Jezak
 Amanda Kokenda
 Andrea and Joe Kuklis
 Carolyn Lah
 Marie Mambuca
 Steven Perdziola
 Erin Pottgen
 Casey Santo
 Jenn Shuplock
 Erik Sigmund
 Joette Smidea
 Dana Wolfe
 Mitchell and Nicholas Woroi
 Anne, Emily and RJ Mihalko



BANDS

Flying sock Monkeys

Nayem
 Katie
 Harrison
 Jason
 Tyler
 Patrick
 Dominic



Blues Junkies

Mike Scheer
 Jim McCabe
 Ed Krux
 Guest Singers: Pam DeLuca
 Logan DeLuca

Jumping Jack Flash

Garrett Andre
 Mike Scheer
 John Macho
 Tony DeLuca
 Ray Mihalko
 Mike Oncea



Support Group Happenings

Central Susquehanna Autism Support Group

Susan Bolig

Our summer family get togethers were a lot of fun. Twenty two people joined us for bowling in June and 36 attended our July swimming party. Our August meeting was well attended for our guest speaker William. William is a college student who is diagnosed with Aspergers. Our upcoming meetings include topics of adolescents and sexuality, ASERT, autism research center, and a rock climbing outing for the whole family.

CSIU Parent Support Group

Kathleen Stropnick

Here in the Danville/Selinsgrove area the third CampEmerge weekend occurred over Labor Day Weekend. Thirty four families gathered for all the fun of camping (several families even pitched tents between the cabins just for fun). Once again, we enjoyed each other, cried sometimes, and marveled at our beautiful children and were amazed at our struggling but strong families. Thank you to ABOARD for recognizing Jerry Stropnick with the Grandin Award for his work on making CampEmerge happen and thrive for 12 seasons.

Lebanon County Autism Spectrum Support Group

Diane Grumbine

The autism spectrum support group of Lebanon County has had another successful year. We are continuing to try to reach new families and are gaining

members at a steady rate. We don't always meet in person but stay connected via email. Our email group is fantastic about responding to requests for help and advice. We have started a facebook page as well. We meet monthly for educational meetings about a variety of topics. One of our favorites was 'acting out' a presentation about how acting can help teach social skills. We all had to participate in the acting exercises, embarrassing but fun. We also had a hayride and bonfire, a Christmas party, a valentine ice cream social with a balloon artist, laser tag, a picnic and a swim party for families to have fun together.

We are excited about the new line up of speakers. We will start with a Back to School Workshop. Future meetings will have presenters about resiliency, a fitness program for kids with autism, starting a GFCF diet and more. Before we know it, October will be here and we'll be off to the bonfire again for our smores and hot dogs. We have an awesome group of caring people that are always willing to share problems and joys and encourage others.

Resiliency Program with Jen Lyrstis. The program consists of an ASD educational training series, a training series on crisis management and coping, a training series on resiliency for parents of children with ASD, and a web-site they are developing to serve as a resource for resiliency and connections to community supports for families.

Parent in Lebanon County Support Group

If your special needs child is 14 years of age or older, ask your school district's Transition Coordinator, or Director of Special Education for the folder from the Department of Education entitled "Secondary Transition Resources". You can also obtain this information from the Pennsylvania Training and Technical Assistance Network (PaTTAN) either by going to their web site www.pattan.net or by phone @ 1-800-360-7282.

It is important for you to know that transition planning for students is required by the Individuals with Disabilities Education Act (IDEA 2004) and Pennsylvania Special Education Regulations (Chapter 14). You have to be your child's best advocate. Do a lot of research, ask a lot of questions, and prepare for every meeting. You must be your child's voice, so speak up

Lancaster County Autism Mommies

Kim Shank

The mission of Lancaster County Autism Mommies (LCAM) is to form an alliance of mothers dedicated to creating circles of support that embrace families touched by autism. It is our desire to significantly impact all aspects of life with autism so that families may thrive in a supportive environment. United we are empowered to promote growth and awareness, to provide education and resources, and to nurture relationships with each other, our children, our families and our community. LCAM hold monthly meetings and events.

**ABOARD has
63 parent support groups
in 48 counties!**

Support Group Happenings—Continued

Adult Autism Advocacy Group

Phil Garrow

We are a group of high-functioning adults on the autism spectrum who are working together to improve the lives of people with autism locally, nationally, and in time, internationally. Our group focuses on advocacy-based initiatives that affect the lives of people on the autism spectrum.

Examples of projects that we are pursuing are:

- The printing and distribution of autism ID cards to be offered to first responders.
- The creation of a national database of autism groups to unify goals between groups.
- The development of autism-safe

online communities.

- The revision of SSDI for the lifetime needs of people on the autism spectrum.
- The creation of an Autism Meeting Place where autism groups can schedule events.
- The development of an autism community house / mixed-use space.
- Advocacy and civil rights action for people with autism in the workplace.

There may be other projects that we will work on in time, or we may choose to pursue other solutions to solve the problems listed above. But the focus of this group will be on advocacy, and will not be social or activity based. Membership is open to anyone who wishes to contribute their time and energy to solve the problems of living with autism throughout one's lifetime.

Biomed Buddies

Chris Perdziola

The Biomed Buddies support group is back from its summer hiatus! Meetings will be held on the third Friday of every month. Upcoming meetings are October 15; November 19 and December 17. The October 15 meeting will be held in the community room of Panera Bread in Monroeville at 4172 William Penn Highway (Rt. 22), conveniently located right off the PA turnpike and 376. This meeting will feature general discussion, a review of materials from the Spring DAN conference and discussion of the Spring 2011 Biomedical Conference ABOARD and Biomed Buddies is hosting. Future meeting locations will be announced. Please RSVP anytime to Chrisoula at biomedbuddies@gmail.com or 412.999.9499.

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- Actively involves parents and other caregivers
- Is confidential

Early Intervention in Pennsylvania is a system of services & supports designed to help families with children who have or who are at risk of developmental delays. In Allegheny County, coordination of services for children between ages birth to 3 years is provided by The Alliance for Infants and Toddlers, Inc.

**Contact The Alliance to make
an appointment:**

412.885.6000
www.afit.org

Parents of Students with Autism: We Are Not Alone

My daughter Mackenzie is ten years old and is like many other ten year old girls in America. She loves music, putting on nail polish, working on crafts, playing outdoors, and being in the company of her pets. Nearly two years ago, she began taking horseback riding lessons and participated in classes at a local horse show. But Mackenzie is not your average ten year old. She is among the growing number of children in the United States diagnosed with an Autism Spectrum Disorder. Her official diagnosis is Pervasive Development Disorder – Not Otherwise Specified. Mackenzie was also previously diagnosed with epilepsy, ADHD, learning disabilities, and vision convergence issues. Her diagnosis of PDD-NOS came about recently through a series of visits with a developmental pediatrician, Dr. Jessica Roesser, at Kirch Developmental Services at Strong Memorial Hospital in Rochester, New York. Mackenzie is what is referred to as “high functioning” autistic with a below average IQ. It was not easy to obtain an autism diagnosis. Parents have to be persistent and diligent.

My husband and I have had to step into the role of advocate for Mackenzie. Most recently, it was with our daughter's elementary school. We admit, it is not a role we are comfortable with as we do not like confrontation and we tend to be too trusting with individuals when they say they know what's best for our child while ensuring us they have her best interest at heart. What we have learned is that our daughter's school administrators do not have her best interest at heart. Mackenzie was being denied an aide to help her through her school day. In February, our daughter began asking to be kept home from school by claiming she was sick. Only we knew she wasn't.

This persisted so we finally asked her why she didn't want to go to school anymore and she said, “Why do I have to go to school? I'm not learning anything anymore. All I do is sit at my desk and color when I don't know what my teacher is talking about.” This was coming from a child that has always had the greatest attitude about school. She would complain on the weekends because there wasn't any school. Last year, I had to beg her to stay home when she was sick and running a fever. She simply didn't want to miss school. When a special needs child loses their desire to go to school, parents are losing half of the education battle.

At our yearly Individualized Education Plan meeting we were told she had not grown academically since her IEP meeting the previous year. As you can imagine, we were quite disappointed because during her third grade year, when the third grade was split into two classes, Mackenzie had her most productive school year to date. This was due to the smaller class size and with Mackenzie working consistently in the classroom with the learning support aide. We are realistic people and have not taken on the mindset that Mackenzie is capable of unobtainable academic goals. But keep in mind, we do have expectations nevertheless. We have been assured by our developmental pediatrician and the doctor that conducted Mackenzie's educational testing that she has not been tapped out in her learning. She has so much more potential. All of the studies we have read and the advice we have received from our outside specialists promote the usefulness of an aide/paraprofessional working alongside students with autism in the regular education classroom. An aide can keep an

autistic student on task and can help with reinforcing the teacher's directions during instruction time since teachers aren't always able to check and recheck with their special needs students (and this does happen on a regular basis.) Aides can also be beneficial to an autistic student by working with them on their poorly developed social skills and also remove them from a situation if the student suffers from sensory overload or becomes disruptive. Mackenzie is not considered a behavior problem. In fact, we have been told she's so quiet, they almost forget she's there. Autistic children love retreating into their own world and this is not a good thing. Idle time means retreat time.

My husband and I were lost on what to do for Mackenzie. We knew what she needed and we knew we had reached an impasse with our school district. While searching the internet, I became familiar with an organization called ABOARD (Advisory Board on Autism and Related Disorders.) I was very fortunate that day when a wonderful woman answered the phone at ABOARD. I explained our situation to her. She went into action by explaining to me what my daughter's rights were under the special education laws. She passionately discussed the *Individuals with Disabilities Education Act*, *Free and Appropriate Education*, and *Least Restrictive Environment*. She also told me about her own autistic child and her experiences in dealing with the school district. She took the time to give me as many contact people from agencies in our area to help us get our daughter

Continued on Page 14

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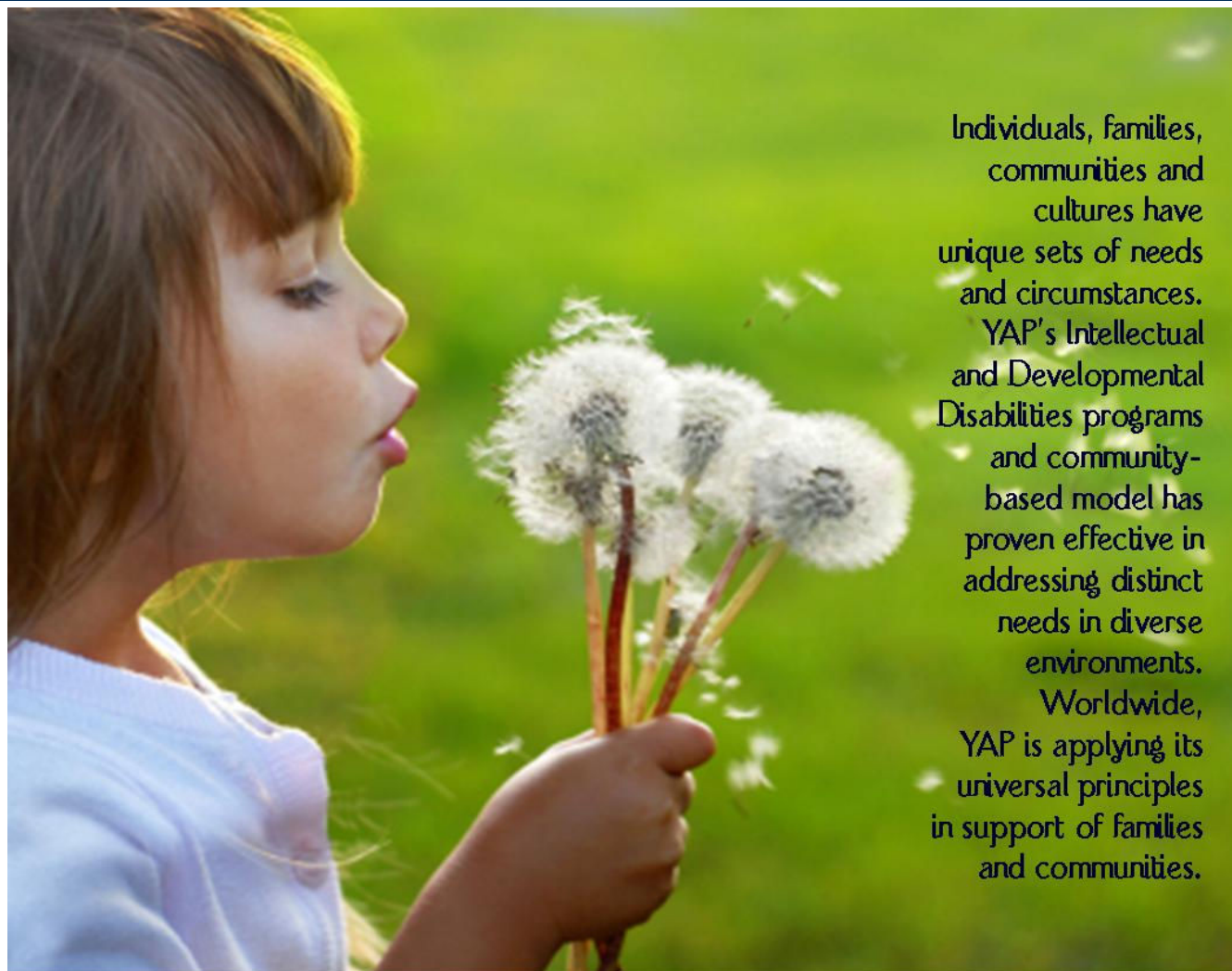
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Making the Connection---Understanding DIR®/Floortime™

DIR®/Floortime™ is the model that guides my treatment as an occupational therapist for children on the autism spectrum. My journey began in 2002 when I attended the International Council on Development and Learning Disorders (ICDL) Annual Conference. There I found myself in the midst of a learning experience that I will never forget. DIR®/Floortime™, presented in part by the late Dr. Stanley Greenspan and Dr. Serena Wieder, co-founders of ICDL, demonstrated a common sense, yet very intricate approach to treatment of autism. Specifically, DIR®/Floortime™ clinicians view the child through a developmental lens (**D**) of functional core capacities. DIR®/Floortime™ clinicians have a very thorough understanding of the developmental capacities (**D**) which are seen in all children, but are challenging for those on the spectrum. These capacities are the ladder to abstract reasoning and complex thinking and support the integration of all the developmental elements (motor, social-emotional, cognitive, language). DIR®/Floortime™ also tells us how to treat the *whole* child; treat with regard to the uniqueness of the individual (**I**) ideally in a multi-disciplinary setting. Treat with regard to the family and key relationships (**R**). As an occupational therapist, this model meshed with the holistic roots of my profession. Add to that focusing on a solid foundation in sensory regulation (another of my passions) and I was impressed!

Specifically, DIR®/Floortime™ coaches caregivers to follow the child's intentions and promote or encourage the

child to initiate responses to his or her world. By having a clear understanding of a child's unique ability to attend and engage, be reciprocal (back and forth interaction), build bridges between ideas and feelings and problem solve, and use symbols to represent these ideas and feelings coupled with individual neurobiological differences such as the body, sensory integration, sensory modulation, allergies, dietary concerns etc..., clinicians and parents learn how best to relate with their child. Coaching parents or caregivers how to understand their child's and their own individual differences and using a child's interests to foster interactions in the context of daily life are my most rewarding experiences. The resultant warmth or shared emotional "connection" that follows is priceless. Dr. Greenspan also explained that once that special connection in "[the child's] world" is made, we can help the child to "...master [his/her] functional emotional developmental capacities" (DIR®/ICDL™ e-newsletter, Sept 2010). For instance, here is the scenario of a newly diagnosed self-absorbed 3 year old child on the autism spectrum who has a very low sensory responsivity, minimal language, guarded engagement, and low tone. He sits and repetitively pats a deep sounding drum. His parent sits across from the child, repeatedly calls his name, and shows him a toy car; but there is no response. Mom says, "He doesn't play like his older brother." I help the parent to understand about first his sensory needs. I explain he is a child who is receiving pleasure from his own system (e.g. hitting the drum and feeling the vibration, and hearing the

sound). I also help her to understand that in order to gain his attention she may need to slow her pace. I suggest that the parent move closer to him in hopes to have her join the activity. Next, I encourage the parent to join in by tapping in the same rhythm on the drum base so that they both are tapping simultaneously---the parent has now followed the lead of his play. She has begun to enter into the child's world; to encourage engagement - trying to relate to him. Then, the child glances up quickly and then back down and continues tapping. Both parent and child pat the drum together at the same rhythm until I ask the mom to playfully put her hands on top of his to stop the drumming. The child stops and pulls his hands. This goes on for a few minutes. Before the child has the chance to resume tapping, I ask the parent to change to a different rhythm. The child again, regards his mother, and puts both his hands down loudly on the drum and smiles. Mother smiles right back! Ah... the social-emotional connection is made! The parent and child have engaged, and the child has intentionally signaled with his affect. They are moving up the developmental ladder. To encourage the child and parent to move along further, I tell the mother to respond in a similar loud bang on the drum which again brings forth a smile in the child. Back and forth the mother and the child take turns beating the drum in loud bangs with lots of smiles. I encourage the mother to turn the drum so they can beat on different surfaces to facilitate problem solving. Her

Making the Connection---Understanding DIR®/Floortime™ - Continued

child keeps returning the drum to the upright position. I ask her to continue to change its position and then, move it to one side and then to the other side and then to her lap, again to keep the interaction moving. They both continue the playing of the drum in these various positions until I ask mom to hide it under a nearby blanket. Mom looks at her child quizzically, he looks side to side, and she animatedly says, "Where is it?" The child spies the cylinder shaped blanket, but mother, on her own, holds the blanket tightly so the child can't retrieve it. (She's getting the idea!). The child begins to grunt and pull off the blanket in an effort to retrieve his drum. I explain to mother to keep holding on tight having the child to work for what he wants. He exclaims, "DRUM!" as he continues with exertion to find his treasure. Finally, I signal for his mother to abate, and he succeeds and collapses in a heap with his drum in his mother's lap, both in giggles.

Now I'll fast forward this example a several years to show you almost the full range of developmental capacities that a DIR® clinician facilitates. This scenario exemplifies the communicative and more in-depth cognitive piece as well. The child is still very fond of playing the drum, and I still use this interest as part of this parent-child play. The child, although he still can be self-absorbed and his reactions to sensory stimuli around him are less than expected, is more dynamic in interaction, and his language has improved. The mother is more adept at reading her son's behaviors to help regulate her son to

enter in the world around him. We start similarly to the first scenario, but both mom and the child are drumming in a rock band together. The play is more creative and focused on symbolic ideas and feelings. He begins drumming while bouncing "patta pan, patta pan pan pan" and mom states to him, "You are a star." He smiles and says, "A BIG star!" "Me too," she adds. I encourage her to ask him where they are playing. The child responds "America's Got Talent." Together, they plan to pretend to be on stage playing to a crowd on their favorite show. "Who is the announcer?" mother asks and the boy points to me. "Me?" she asks grinning in jest, and he shakes his head. "Who?" she asks again waiting for a response, and then he says my name. I announce, and they play all awhile elaborating on ideas *back and forth*---integrating things such as technical difficulties, a cheering crowd, and then facing the judges. We determine that I will be the three judges---Two of them vote "yes" or thumbs up, and one votes "no" or thumbs down. Interlaced in this interactive make believe, we discover whether he was "sad, frustrated, tired, excited or happy etc..." depending on the situation and try to expand on each. Through this experience, he is learning to develop better problem solving, more complex thinking and to communicate, not only creatively, but also with emotional themes. He is learning "why" he is feeling emotions and making logical sense of his creative play. His interactions are swifter, and he is better able to relate and express himself symbolically (e.g. holding the make believe images in his mind, acting out pretend, and expressing his needs,

ideas, and emotions.) It is evident that his developmental capacities are much more multifaceted than from where we first began.

Overall, at the start while initially the child is able to maintain a regulated calm state, he was not socially interested. As the mother moved in and began to join what was pleasing for him, he began to take notice and the two demonstrated shared attention to play. As she continued enticing him and playfully obstructing his tapping then, and changing the rhythm, they were able to relate to one another in a very meaningful playful interaction for both. As the play continues, eliciting more emotional responses, moving toward back and forth turn taking of the drumming, encouraging problem solving with different placements and finally, the child's expressions of creative play and emotional ideas, illustrate movement up toward higher developmental capacities.

It is important to realize that not every child will move through the levels at the same rate. A child may move faster, another may progress slower; there may only be fractions of one level while another is robust, but the connection and resultant success can occur and make the quality of life much better!

There are many aspects of DIR®/Floortime™ which allow the parent and family to be enhancers of the road to a happy life. Parents or clinicians can first

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Parents of Autistic Students: We Are Not Alone - Continued from Page 9

what she needed at school. I found out that Mackenzie was eligible for grants and she was entitled to other educational aids and devices such as specialized software to help assist her with her school work and that the school district was responsible for providing it to her. She also informed me that she was putting an information packet together for us which she would be sending out later that day (we received it in three days.) I got the push I needed. I knew we were in the right over our disagreement with the school district, but thanks to ABOARD, now I have the tools necessary for us to get our daughter what

she was entitled to at school. Through her contact list, we found a regional special education advocate who truly got the ball rolling for Mackenzie's cause. Ned Whitehead met with us at our home and reviewed Mackenzie's medical reports, educational testing evaluations, specialist recommendations, and her current IEP. Ned devised an individualized game plan for us to prepare us for our mediation. I am happy to report that on July 17, 2010, at our mediation meeting, we reached a very beneficial agreement with our school district. The word "mediation" sounded so daunting to us before, but parents should not be

afraid to take on their child's school. The mediator sent in by PaTTAN (Pennsylvania Training & Technical Assistance Network,) was kind, thorough, and very, very empathetic to both Mackenzie's needs and that of our school districts capabilities. What we have learned, there are many dedicated individuals out there, like ABOARD, to inform parents and fight for the rights and needs of special needs children. ABOARD helped enable us to find our voice and we were able to get Mackenzie what she needed

By Carol Stringham

Making the Connection---Understanding DIR®/Floortime™ - Continued from Page 13

find out more about DIR®/Floortime™ at <http://www.icdl.com/> for resources such as listening to podcasts by Dr. Greenspan, connecting with families currently using DIR®/Floortime™, accessing an e-library, and viewing ICDL book lists to name a few. In particular, some recommended books for DIR®/Floortime™ are *Engaging Autism* and *The Special Needs Child* both by Greenspan and Wieder.

To become a certified DIR®/Floortime™ provider, an advanced clinician, involves several steps. Certification requires much dedication to the program including attending intensive on-site DIR® Institutes, organizing case-study presentations, completing ongoing tutoring with certified mentors, and finally preparing a written presentation. After attending this past summer's Institute, and immersing myself in the DIR®/Floortime™ model, I

am committed to continuing the certification process.

Last, during my recent attendance to the DIR® Institute, I had the opportunity to personally meet supportive members of the ICDL faculty. ICDL faculty teach and present all levels of courses and are highly experienced in training professionals. They are selected by senior faculty and participate in a training program to ensure they are strong tutors and trainers. This program is co-directed by Dr. Serena Wieder (Director of the ICDL Institute) and Ruby Salazar, LCSW, BCD (senior faculty). Ruby Salazar is also the Pennsylvania Senior DIR®/Floortime™ Faculty and can be reached at [HYPERLINK "mailto:rubysa2@gmail.com"](mailto:rubysa2@gmail.com) or [ruby-sa2@gmail.com](mailto:rubysa2@gmail.com) for questions or consultation.

By Stacy Sue Rosello, MA, OTR/L

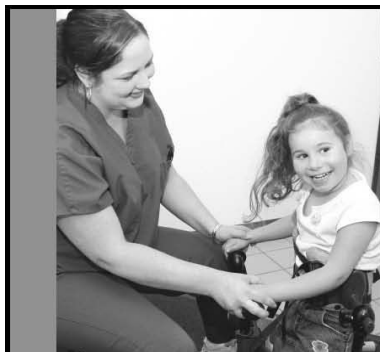
For further assistance contact:

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Stacy is a SIPT certified occupational therapist and DIR® CI candidate with 17 years of experience with children using Sensory Integration. She will be serving children aged 0-5 and their families in their homes in the South Hills of Pittsburgh. Stacy plans to continue to pursue her certification in DIR®/Floortime™ and carry on her passion of helping those affected by autism spectrum disorder. Her small private practice, Embrace the Child, Ltd. will be accepting new clients in mid/late Oct, 2010.



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A Sign of Strength: Building Collaboration through Advocacy in Schools

A few years ago when I attended a conference for parents of children with special needs, I noticed a button one of the conference organizers was wearing. It said "asking for help is a sign of strength". I have remembered that button for these last many years, and have shared the wisdom of those few, simple words, with many families and individuals faced with the challenges of disability. As I traveled the unpredictable, twisting road of raising and advocating for a child with significant special needs, I never hesitated to ask: I asked for information. I asked for resources. I asked for help. Like you, I had been thrown into this strange new world without preparation and with great surprise! Through the generosity of experience of other parents, educators and service providers, I learned to find my way around this very foreign world one day at a time, one step at a time. With the help of others—and especially with the help of my daughter with intellectual and physical challenges—I slowly became "expert". Now, 24 years later, I have the same advice to all who come to me: Ask questions. Ask for help. It is a sign of strength, and through questioning you will become stronger.

As we begin another school year, you may have many questions concerning the education and supports of your child with special needs. Knowing who, what, when, where and how to ask these questions is crucial in the developments of a strong, collaborative educational team for your child. As every parent of a child with autism knows, one size does not fit all. Autism comes in many different shapes and sizes. Creating a truly Individualized Education Plan (I.E.P.) for your child with Autism which will insure that they are getting a Free, Appropriate Public Education

(F.A.P.E) in the least restrictive environment (L.R.E) is a collaborative process involving many people and many questions. The relationship with your child's school district is one of the longest professional and personal relationships you will have. It last from kindergarten until, in most cases for students with special needs, your child turns 21. Learning to ask for help will make you a better advocate for your child and a better partner with his educational team. You do not need to do this alone.

How do you ask for help? Through advocacy support. Advocacy comes in many shapes and sizes, and can be anything from attending workshops and seminars to teach yourself how to be a better advocate, all the way to hiring an attorney to represent your interests with the school district. An advocate or an attorney can help you learn the questions you need to ask to navigate the special educational system for your child.

When should you call in an advocate or an attorney to help you navigate and advocate? It is never too early to call in an advocate. Many people wait until there is a "real problem" before they call in an advocate or an attorney. The fact is, by the time there is a "real problem", then much of the time and effort of the advocate is spent in undoing past wrongs rather than building positive, collaborative relationships. Calling in an advocate or attorney early can in fact prevent misunderstandings or mistakes from being made, increase collaboration, and decrease the likelihood that you will need to end up in a due process hearing. As our mother's used to say, "an ounce of prevention is worth a pound of cure".

Who can be an advocate? An advocate can be almost anyone from your friend or

relative who is merely an extra set of ears at a meeting, to a professional advocate from a non-profit agency or a private advocate or even an attorney. An advocate can be an outside support person such as a private speech or occupational therapist or a reading specialist. Understanding the issues will help you determine what type of advocate you need and when. If you feel lost, and don't understand the issues, a consultation with an advocate or an attorney can often help you identify your issues, understand your rights and responsibilities, and develop a strategy. Knowing what type of person to bring in and when can be a crucial building block to collaboration with your child's school district.

What can an advocate do for me? Educational specialists, advocates and attorneys all have their specialized roles to play in helping you secure FAPE, yet there is also a lot of overlap. How can each of these professionals help you and how do you decide on the most appropriate professional? Understanding the roles and limitations of each profession may help.

Advocates can provide information and resources about special education rights. They can guide you through the steps you need to take when asking for educational supports. They can help you identify when the district may be violating your child's rights. Advocates can teach you skills you will need to create and sustain collaboration. They can teach you how to be an active listener, understanding the interests and positions of other team members. They can teach you how to move from emotions to advocacy. They can be your voice, and teach you how to find your own voice. When collaboration fails, they can

A Sign of Strength: Building Collaboration through Advocacy in Schools - Continued

guide you through the process of accessing your due process rights. They often work hand in hand with attorneys. Advocates cannot represent you in a legal proceeding of any sort. While many advocates can and should be knowledgeable about the laws governing special education, they cannot give actual legal advice. The right to legal representation is exclusively reserved for licensed attorneys. Advocates may attend and support (not represent) families in any legal proceeding, including mediation sessions or due process hearings.

Attorneys should be called in when it is clear that other advocacy and collaboration efforts have failed. If there are any truly legal disagreements, then an attorney should be called in. If it is clear that the family will have to file a complaint for non-compliance or ask for a due process hearing, then an attorney

should be consulted before any paperwork is filed, if possible. An attorney can attend any meeting with the school district except a mediation session. In Pennsylvania, special education mediation sessions are reserved for advocates only. An attorney can come to an IEP meeting, if appropriate. Attorneys can help you engage in an effective letter writing campaign to get the services and supports you need for your child. Attorneys' can help identify where there has been a violation, and can evaluate the strength of your situation to determine whether or not a due process hearing is appropriate. One of the advantages of using an attorney can include opening doors to the "higher powers"—the school district's attorneys. If there really is a legal issue to resolve, it is best to get attorneys involved as soon as possible.

A good advocate or attorney will help you

create a foundation for an educational plan that will work for your child. Never be afraid to ask for help. It is a sign of strength, and through asking you will grow stronger and your child will get the education to which he is entitled.

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Pula Rule is a parent, an advocate, an attorney specializing in issues facing people with disabilities. She represents parents who are trying to secure a free and appropriate education for their child. She has been the parent of three children with disabilities for over 20 years, and has worked in the educational, medical and community systems helping people secure appropriate supports and services.

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Rick J. Murray, LSW, BCBA, Chief Operating Officer
Catherine A. Hughes, Family Support Coordinator
1-866-4-FBR-ASD; autismservices@familybehavioralresources.com



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AHEADD	Glade Run Lutheran Services	Stern Center for Developmental & Behavioral Health
Alliance for Infants & Toddlers	GuyauxMandlerMah	Tri-Medical Rehab. Supply
Alliance Health Wraparound	Integrated Care Corporation	University of Pittsburgh
AVID Learning Center	Ligonier Valley Learning Center	Autism Center of Excellence
Barber National Institute	Midwestern Intermediate Unit 4	Value Behavioral Health of PA
Bayada Nurses	Nathan Speech Services	Watson Institute
Children's Institute of Pittsburgh	New Story	Wesley Spectrum Services
Community Care Behavioral Health	NHS Human Services	Western Psychiatric Institute and Clinic
Comprehensive Children & Family Services	PACE School	Westmoreland Case Management & Supports, Inc.
Costa Law Offices	Pediatric Therapy Professionals, Pediatric Therapy Specialists	Westmoreland County MH/MR Program
Diversified Human Services, Inc.	PLEA	WJS Psychological Services, Inc.
Dynavox	Rehabilitation Specialists, Inc.	Youth Advocate Programs, Inc.
Easter Seals Western PA	River Speech & Educational Svcs.	
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The Advisory Board on Autism & Related Disorders (ABOARD)

2010/11 ABOARD Membership Form

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We're on the web!
www.aboard.org

Our Core Principles

ABOARD believes that because there is considerable debate throughout the autism community regarding therapies, inclusion, autism cause, vaccine impact, and the potential effects of proposed legislation, our policy is to inform. We trust individuals to assimilate the information and make the best decision for their children, clients and students!

We believe that families are entitled to accurate and timely information, require emotional and practical support from other families grappling with comparable challenges, and often need advocacy assistance and training to maximize availability and utilization of treatment educational and vocational possibilities required by law.

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