

The ALL ABOARD NEWS



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

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"Focus on the student's strengths and not the disability."



Volume XII — Issue 6

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tran-si-tion: passage from one state, stage, subject, or place to another

Transition is such an overwhelming concept for parents of children with disabilities. What are they going to be when they grow up? Where will they live? Who will help them maximize their potential and possibilities?

With our typical children, it's a lot easier. We teach them responsibility, respect, work ethic, and open the door. With our children with ASD, it is a different story.

On November 16, ABOARD invited Jackie Marquette to talk about transition to adulthood. Her conference, "Walking the Path" Through the Transition Years for All Youth with Disabilities", was fabulous and we had 24 transition-related exhibitors. Over 140 parents and professionals attended and came away with very good stuff. And the food was fantastic!

Some of the comments about what was most useful in the training:

"The encouragement to "think outside the box" when planning for individuals."

"It helped in realizing all the possibilities that are out there."

"The exhibitors were great and answered all my questions."

"This training was an excellent way to determine needs and brainstorm."

"Focus on the student's strengths and not the disability."

"The speaker gave hope to many parents that their ASD kids will someday be contributing members of society. It was quite uplifting."

"Affirmed ideas and strategies that I have been using for years!"

"It gave me hope for the future."

Here are some additional resources:

Life Journey Through Autism: A Guide for Transition to Adulthood:

<http://www.researchautism.org/resources/reading/documents/TransitionGuide.pdf>

Colleges that identify themselves as having some Asperger support on campus:

<http://www.larsperner.com/autism/colleges.htm>

We would like to offer thanks to all the exhibitors who gave parents and professionals good information: AHEADD, AHEDD, Allegheny County DHS & OBH, Americorps, Bureau of Autism Services, CCAC, Community Options, Competitive Employment Opportunities, Inc., Elks Home Service, Fair Housing Partnership, Greater Pgh Supported Employment Association, LifesWork, OVR, PEAL, Pressley Ridge, Social Skills Coaching by Wendy, Step by Step, Inc., The Children's Institute, Three Rivers Center for Independent Living, UCP-CLASS, UPMC Vocational Center.

Thank you to all the parents and professionals who attended this conference. We hope we helped your family and clients. If you have any questions, as always, call ABOARD.

ABOARD LENDING LIBRARY



ABOARD has added over 60 new titles to its library! There is *No Membership Required* to access over 700 books, DVD's and videos. All you pay is the cost to ship the items back! Please see our website for an updated list or contact our office to have a list mailed to you.

To help share knowledge and keep the library growing, ABOARD accepts donations of resource items, books, videos, DVD's, etc. that you no longer need. Donations are tax deductible!

Director's Message

With 2008 upon us, we are embracing it with anticipation and excitement. Many interesting things are happening at ABOARD, and I would like to take this opportunity to share with you what lies ahead of us.

Membership

As you have already seen, ABOARD has suspended the yearly membership for individuals. In the past, the membership has been misunderstood. Although ABOARD fielded thousands of inquiries yearly from non-members, some believed that one had to be a member in order to receive support services. Our past membership merely gave access to not only our newsletter, but to our wide variety of books, CDs, tapes, and DVDs in our lending library. Going forward, the confusion is over. ABOARD feels that it is important that all information we have to disseminate is available to all. We want to make sure there is no barrier for a family to receive the much needed help they are seeking.

Library

With over 700 titles, our library is a wonderful resource. ABOARD will continue to promote the library as well as add the newest sought-after titles as they are released. It is a decent-sized project to maintain a viable offering of books, CDs and DVDs. Some people enjoy reading while others like to listen or watch their learning material. It is important to have materials on a broad array of topics to ensure that what we offer is matched by the demand.

Support Groups

ABOARD is a strong advocate of the need for support groups. Not everyone desires to participate in these small group settings, and many more have difficulty finding the available time. The demands on our time are many. Families, jobs, hobbies and personal downtime all compete for the same 24-hours of our day. It is our mission in 2008 to make sure that we are providing an atmos-

phere in which all of the available groups get their information out to the public. We also are going to make sure that the groups themselves get the support they need to facilitate interesting social and educational experiences. We understand that groups start and thrive sometimes around particular interests, age groups, or themes. We look forward to a time when there are many diverse groups in many geographical areas. It is part of ABOARD's 2008 focus to support all of these groups, so that they are able to focus on the programming and welcoming of newcomers.

Board of Directors

The board of directors for ABOARD has new officers. We welcome Elliot Frank as chairman, Andrew Fellowes as vice-chair, Steve Crane as treasurer, and Chris Eastly as secretary. We also thank David McMaster for his service to ABOARD as chairman for the last 4 years and are happy that he will remain as a board member. The board of directors members are: Elliot Frank, Andrew Fellowes, Steve Crane, Chris Eastly, Nancy Albinini, Beth Rom, David Thayer, Chris Perdziola, Andrea Turkheimer and David McMaster.

Outreach

ABOARD believes that proactive outreach into the community is important. Look forward to ABOARD being involved in various programs over the next year to help children and parents in the educational setting, to help foster a greater understanding of autism in urban areas, and to continue the autism education and support to primary care physicians.

We welcome everyone to 2008, and look forward to 2008 welcoming us. Please do not hesitate to call ABOARD for your questions or needs; and make sure to pass on our phone number to another individual or family. Have a great year.

Karl W. Smelser, Executive Director

8th ANNUAL GALA AND CASINO NITE

Saturday, January 26, 2008 was an evening of dining, dancing, music, and gaming for those who attended the 8th Annual Gala and Casino Nite that benefited ABOARD and CeFAR. The gala was emceed by Michael Bartley from WQED. Awards were presented for the following:

Outstanding Community Outreach

Mary Limbacher, Cranberry Cares Support Group

Outstanding Professional Partner

Rick Murray, Family Behavioral Resources

Grandin Award

Nina Wall-Cote, Department of Public Welfare

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Special Thanks

Lori and Dave McMaster, Gala and Casino Night Chairs, all our wonderful volunteers and those who donated gifts and services.



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What is the Professional Advisory Council (PAC).

ABOARD's Professional Advisory Council is comprised of a group of professional individuals that work in the autism community. This Council helps promote resources, information and latest technology/ trends to help those with autism while providing guidance and support to ABOARD.



Nathan's Story

Nathan Frank's parents, Elliot and Melissa, never could have suspected nine years ago that he would be the bright, capable, determined and engaging young man that he is today.

That was when they received the diagnosis of an autism spectrum disorder known as Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). The chilling prediction from those familiar only with the more severe forms of autism was that Nathan, then 4, would never be able to express himself or have empathy.

"But we made a vow then that he would learn to say 'I love you' spontaneously and mean it," Elliot said in a recent interview.

Today, the Wexford residents offer eager testimony to not only their son's far greater accomplishments but the imperatives of early diagnosis and aggressive intervention.

Now a seventh grader at Marshall Middle School in the North Allegheny School District, Nathan has met his challenges head-on. And with the help of his parents, teachers, aides and therapists, he has reached his goal of becoming an honor roll student and is looking forward to a career as an aeronautical engineer.

He also recently accomplished the rigorous nine-month preparation for his bar mitzvah on Sept. 29 at Temple Ohav Shalom. That rite required significant memorization and learning Hebrew to read passages from the Torah and chant before members of the congregation.

Nathan, the second of three sons, was a seemingly typical 4-year-old and his parents suspected nothing unusual when preschool teachers noticed that he was easily startled by loud noises. They recommended he be examined.

Melissa, now a rehabilitation physician at Heritage Valley Health System, was able to get Nathan in to see a child development specialist and the PDD-NOS diagnosis was made.

PDD-NOS, also known as atypical personality development, encompasses cases of unusual sensitivities, impairment of social interaction and communication but without other common indicators of autism.

They immediately got Nathan treatments through the D.T. Watson Foundation School for Autism in Sewickley. Intensive therapies were undertaken to provide him with one-on-one assistance in socialization skills, understanding others and communicating with them.

This therapeutic staff support, or TSS, continued until Nathan was in school, helping him interpret words and put words to his feelings. He continued in this regimen and had a personal classroom aide through first grade, but after that was able to do well enough in school without that added help.

With assistance of additional private therapy under Dr. Joseph Strayhorn Jr., Nathan and his parents gradually learned what he needed to work on, and how to go about it.

"By six years old he learned the language of what he needed," Elliot said, crediting his son with the awareness and hard work that have brought him so far in the years since. "You need to remind yourself every so often what we were doing just a year ago."

"Fortitude" and "flexibility" have become Nathan's watchwords as he approaches his challenges of dealing with things that disturb him.

"My weakness is fire alarms and loud noises," Nathan says today, and when he is confronted by a startling noise he reminds himself that he has the strength to overcome his instinctive reaction. "Fortitude is the right tool for the job."

Likewise, flexibility is important in Nathan's toolbox for managing the unexpected. "It's just a matter of common sense – reality. You don't always get what you want or things don't go your way," he says.

Nathan has faced a lot of issues and done very well, his mother says with pride. "In many ways he's a typical teenager who just needs a little extra supervision." She notes that a parent's role with a special needs child is complicated by considerations of how much is typical and how much is different. "Every child has needs; with Nathan it's just a little more intensive. Now he's facing typical teenage issues, but perhaps with more awareness and a bit higher level of anxiety."

Family dynamics also require some balancing, Melissa said. Isaac, 16, and Noah, 8, are understanding and supportive of their brother's special needs, "but maybe they have to struggle a bit sometimes for their share of attention."

"Nathan can be edgy," Melissa said, "requiring us to be on the alert for problems that can develop suddenly. He can quickly anticipate or 'awfulize' about how things might go wrong. You just have to catch stuff and get the right support early," she said.

But his heightened awareness of these issues also helps him be a planner to anticipate and cope with the typical teen challenges, she said. "He's so intuitive, perhaps because of all his training – more in tune with his feelings. His perspective is so impres-



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Nathan's Story Continued ...

sive; he's very astute and sensitive – always processing.

"Never underestimate your kids and what they can accomplish if you're willing to get and give support for what they need," she said.

His father is grateful for Nathan's hard work and progress and all the assistance he has had over the years. "As he grows, he knows he'll have a career, make friends and be socially active. He works harder than anybody I know to solve a problem. He doesn't let anything stop him. Sometimes he gets frustrated or angry, but he just pushes forward," Elliot said.

Elliot is chairman of the ABOARD board of directors as well as administrator of Temple Ohav Shalom. Hence he is also especially proud of Nathan's success in his study of Hebrew since he was eight, and completion this fall of his bar mitzvah that marks a young man's readiness to accept adult responsibilities in the practice of Judaism.

A part of that observance, dubbed humorously by Nathan as his "Bart Mitzvah," was patterned after the TV show, The Simpsons, with Elliot cast in the role of Homer Simpson and Melissa as his wife Marge. His dad attributes that to Nathan's being blessed with imagination and a sense of humor.

Melissa said, "He did a fabulous job with no special considerations. He's come so, so far. He greeted everyone, worked the crowd and shook everyone's hand. Who knows what he'll eventually be able to do?"

It's not only been his parents who understand Nathan's progress.

"A lot of people feel like I've improved myself and made some big accomplishments in my life. The help I've received has allowed me to function better and give me more opportunities. I'm gradually making it," Nathan said.

"Making it" has included mastering the skills to direct his own bar mitzvah. Rabbi Art Donsky of Temple Ohav Shalom said of Nathan during that rite, "You remind us how special each one of us is and how much we have to offer."

According to Rabbi Donsky, students begin weekly religious training in kindergarten and first grade, and in the second grade learn the Hebrew alphabet. In third through sixth grades they spend two hours one day a week after school. And 10-12 months before the bar mitzvah (or bat mitzvah for girls) they receive instruction individually or in small groups with a variety of tutors.

The final three to four months involve intensive training with the rabbi. While this is true of all students, it especially played to Nathan's learning style and avoided distractions inherent in large groups, Donsky said.

This training involves both learning to read and understand Hebrew and memorizing prayers and chants from the Torah. Memorization doesn't come easily for many students today because they're not required to do it much in school nowadays, Donsky said. But, ironically, students like Nathan often excel in memory work because they've had to memorize much in overcoming their learning challenges.

All this work pays off in a tremendous sense of accomplishment, and in Nathan's case showed how great his abilities are when he puts his mind to them and focuses. "Nathan learned really well; he was very focused," his rabbi said.

Nathan's bar mitzvah also involved a brief speech that included a reference to his struggle with autism.

"Like Moses, I have had to learn to be a good communicator," Nathan said. "Moses spoke with a stutter, and I had to learn how to communicate in spite of my autism. This is why I realized that Moses had to have fortitude and courage to confront God's power. I too have had to learn fortitude and courage to confront those things I feared and didn't understand."



Nathan with Cantorial Intern Tifani Katof and Rabbi Art Donsky

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All Abilities Camp Fair



On February 9, 2008 Aboard hosted an All Abilities Camp Fair at the Mall of Robinson.

The fair included information on:

- Camps for typical children and those with disabilities
- Inclusion friendly camps
- Full and half day programs
- School and preschool age camps.

There were also funny visiting Characters throughout the day.

- Eat n' Park Cookie
- Build-A-Bear Bear
- Chick-fil-A's Cow
- King's Restaurant Frownie
- Aunt Annie's Pretzel

Thank you to all the companies listed above for providing entertainment for the event.

A special thank you to all of the families that attended to help make this year camp fair a great success and to our wonderful exhibitors.

Baierl Family YMCA
 Camp ACHIEVA
 Carnegie Museum of Natural History
 Community Care Behavioral Health
 Computing Workshop
 Conductive Education of Pittsburgh
 Family Behavioral Resources
 Family Services of Western PA
 Milestones Community Healthcare, Inc.
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 UCP Kids
 Variety the Children's Charity
 The Watson Institute
 Wesley Spectrum School Therapeutic ESY
 Wesley Spectrum Services, Family & Child Development Center,
 Therapeutic Creative Arts Program
 Western Psychiatric Institute and Clinic

Policy on Timing and Method of ESY (Extended School Year) Determinations

The timing of an ESY determination is dependent on whether the student is a member of the "target group" [as defined by the Armstrong guidelines]. Students in the "target group" are those students with a severe disability, such as:

- Autism/pervasive developmental disorder
- Serious emotional disturbance
- Severe mental retardation
- Degenerative impairments with mental involvement
- Severe multiple disabilities

The parents must be notified by their LEA of the annual review meeting in order to ensure their participation. For purposes of an extended school year eligibility determination, the LEA must make the determination of the need in a timely manner so that children with disabilities who require ESY services in order to receive FAPE can receive the necessary services. The IEP review meeting must occur no later than **February 28** of each school year for the "target group" (as described above). This date may require the LEA to reschedule the annual IEP review, or conduct a separate ESY IEP meeting for this review.

Notice of Recommended Educational Placement (NOREP), containing the IEP team's determination regarding ESY eligibility, is to be issued to the parent in a timely manner. If the child has been determined to be eligible, the program specifics must be included in the IEP. This is to be done no later than **March 31** of the school year for students in the target group.

It may not be possible to meet the recommended February 28 consideration for a student in the "target group" if the student transfers into the LEA after that date. However, districts and charter schools should remember that if a student enrolls who has an ESY program listed on his/her IEP from another PA school district, that determination of eligibility and program content constitute the student's "status quo" and must continue to be provided until the parent agrees to a change, or a change is authorized through the special education hearing and appeal system. For a late enrolling student for whom an ESY determination has not been made, the decision as to ESY service eligibility or non-eligibility and program content must be determined at the IEP meeting.

For more information on ESY please visit <http://www.able.state.pa.us/kl2/cwp/view.asp?A=11&Q=67441>



ABOARD AUTISM WALK

Advisory Board on Autism & Related Disorders (ABOARD) is proud to represent Autism at the Walk for a Healthy Community presented by Highmark Blue Cross Blue Shield



May 3, 2008 at Heinz Field
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INFANT SIBLING STUDY

WHAT IS THE PURPOSE OF THIS STUDY?

To study vocal and motor development in infants who have an older sibling with autism.

WHO WILL BE INCLUDED?

English-speaking families with an infant younger than 5 months and an older child already diagnosed with autism. Infants must have been born at term and without complications.

WHERE AND WHEN DOES THE ACTUAL TESTING TAKE PLACE?

All observations will take place in the family's home at a time convenient for the family. At 36 months, children and families will come to the University of Pittsburgh for a diagnostic evaluation.

WHAT IS INVOLVED?

In-home observations will occur once a month from the time the infant is 5 months old until s/he is 14 months old, with follow-up visits when s/he is 18, 24, and 36 months old. This is a total of 13 home visits, each expected to last approximately one hour. During these visits, we will videotape infants and caregivers as they engage in everyday household activities and play together. We will also ask caregivers to answer questions about their baby's development and to complete some questionnaires. Between visits, we will ask caregivers to keep track of early motor milestones in a baby book provided by us, and to make audiotapes of their infant's vocalizations using a tape recorder provided by us.

WHAT ARE THE BENEFITS?

There may not be any direct benefits to participating families. The general benefit of participating in this research is to contribute to scientific knowledge that may improve our ability to identify early indicators of childhood autism.

WHAT ARE THE RISKS?

There are no known risks associated with participation in this study.

WHAT IS THE COMPENSATION?

Participating infants will receive a small gift at the end of each session. At the end of the study, families will receive their baby book, a compilation videotape of their infant with clips from each of the observation sessions, and \$250.

FOR MORE INFORMATION CONTACT:

Dr. Jana Iverson, 412-624-6160
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USEFUL LINKS:

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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.

Advisory Board on Autism and Related Disorders

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