

The ALL ABOARD NEWS



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

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***“Together,
pictures, device
and speech are
building blocks
to progress.”***



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Summer 2008

Welcome to the not-so foreign world of AAC (Augmentative and Alternative Communication)

When autism compromises a child's ability to speak or leaves them completely non-verbal, families and teachers may turn to the world of augmentative and alternative communication (AAC) for solutions. Little if anything about AAC is truly foreign. A collective term for the options available for those who struggle with speech (or its absence) and their communication partners, AAC is about promoting meaningful human interaction.

Universally associated with electronic speech communication devices and less sophisticated technologies such as manual communication boards and picture symbol books, AAC also encompasses forms of self-expression that we all use naturally – facial expressions, body language and written notes, for instance. Rarely do AAC modalities work in isolation. Successful communication is usually dependent on the interplay of communication partners and multiple modalities that may include speech.

Communication tends to be an overwhelming experience for many children with autism, so the process of integrating AAC into their lives is best approached gradually, sensitively and with openness to the communication modalities most comfortable for the child in the present moment. Modalities used to convey the desire for a soft drink, for example, may range from a verbal approximation (“I...pop”) to a visual approximation (pointing at billboards advertising drinks while riding in the car) to leading an older sibling to the kitchen. Through repetitive modeling, the child may add a speech-output device to the mix, first to say “Pop, please” with prompting and the press of a single button and eventually delivering the fuller message, “Can I have some pop?” by selecting a sequence of buttons independently.

The importance of regarding each modality as the child's voice rings true for the families and teachers of children attending The Sheila and Milton Fine Classrooms for Students with Autism at The Day School at the Children's Institute of Pittsburgh involved in a research partnership between The Institute and DynaVox Technologies, a leading developer of AAC solutions. A transformation of communication skills is occurring as the students learn to express themselves using the DynaVox V, a portable speech communication device whose dynamic display changes according to their selection of digital images to convey messages. By using it, some students are becoming more verbal while others are increasing their independence and spontaneity. For others, the technology enhances and simplifies previously learned ways of communicating such as pointing to pictures on kitchen cupboards showing items inside. Together, pictures, device and speech are building blocks to progress.

One snare to avoid while teaching new communication modalities is eliminating the ability to use established ones, writes Marge Blanc, M.A., CCC-SLP, a speech-language pathologist and founder of Madison, Wisconsin's Communication Development Center for children with autism spectrum diagnoses, in the May-June 2008 edition of *Asperger's Digest*. She also notes the capacity of children with autism spectrum disorders to bring new supports and challenges to each moment of the learning process.

Such support and resilience may be the keys to success.

By Linnea McAfoose, M.A., CCC-SLP
Clinical and Product Manager
DynaVox Technologies

Chairman's Message

It has been an exciting quarter in the autism world. On Wednesday, July 9th, Governor Rendell will sign into law one of the most comprehensive autism insurance bills in the entire country. Pennsylvania will mandate coverage by private insurers for autism services up to \$36,000 a year until age 21, beginning in 2009. The insurers must use the same standard of medical necessity that the Commonwealth uses in its medicaid coverage.

This bill is the result of a lot of hard work by many people. Speaker of the House Dennis O'Brien, Secretary Estelle Richmond and Governor Rendell have all pushed hard for this bill. The Bureau of Autism Services, a creation of the Rendell administration under Speaker O'Brien and Secretary Richmond, also worked hard. Speaker O'Brien has championed the cause of autism for years. But this is really the result of the hard work of us, the parents of our children on the spectrum. The Autism Task Force Report was developed by the hard work of parents throughout the Commonwealth. The many organizations which supported Speaker O'Brien in his efforts are made up of parents. Many of these organizations worked tirelessly in the days leading up to the bills passage, emailing us updates and calls to action. It was not just the politicians but we, the parents, who made it happen. And while everyone should be sure to thank their house members for supporting HBI 150, please don't forget to thank yourselves! You are the experts who take care of your children and know what is needed and what is best for them.

In spite of this success, there is a troubling side. Once again, there is the divide among different organizations about who did what; who was "right" and who was "wrong". There is quickness in our autism world to judge motivations and attack individuals. I am NOT singling out any one person or organization! There are many involved. ABOARD may even be perceived as being wrong by some on the issues. Knowing as many of you personally as I do, I know that not one of you is mean spirited or wants anything but the best for their child and everyone else's. The autism community in Pennsylvania is at an important crossroads: We have a government based bureau, we have a great insurance law, and we have political support. But we must find a way to walk down a *common path* to support the needs of our children and families. We all expend a lot of time and energy daily taking care of our children and the rest of our family. We shouldn't fight unnecessarily amongst ourselves. It is destructive. We showed that the autism community, with all its diversity, can come together as a coalition quickly when needed. Let's keep that spirit alive.

If you want to read the bill, here is a link:

<http://www.legis.state.pa.us/cfdocs/legis/PN/Public/btCheck.cfm?txtType=HTM&sessYr=2007&sessInd=0&billBody=H&billTyp=B&billNbr=1150&pn=4133>

I hope the rest of your summer is safe and fun.

- Elliot Frank, Chairperson

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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.***

A Special Thanks to our Recent Donors!

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In Honor of Pamela Longmire
Deb Dorsey and Family

Matching Gifts:

Dorothy Brailer/PNC Foundation
Katherine Fulton/Citizens
Financial Group

Grants:

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The Pittsburgh Foundation.

Special Thank You:

Brothers of the Kappa Delta Rho
Fraternity, Iota Alpha Chapter, at
the University of Pittsburgh in
Johnstown for holding an autism walk
to benefit ABOARD at Richland
High School, Richland, PA

Del and Jennifer Suppo

for their ongoing support selling
Autism awareness ducks to
benefit ABOARD.

Autism Speaks, Autism Help
Network, Family Behavioral
Resources and FBR Bridges
to Hope for sponsoring the free
family swim night.

Donte's Pizzeria

for sponsoring a fundraiser to
benefit ABOARD and to the
local companies that supported d
Donte's Pizzeria efforts:

Amel's Restaurant
Clearview Federal
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Eat'n Park

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LA Fitness
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Union Finley
Woody's Dog Bath
Yellow Book

Garland Insurance Agency
and Morgan's Restaurant for
tips and donations collected from
Guest Bartending Rich Garland
and Diane Berkebile.

Thank you on behalf of our
Broad of Directors and the
tens of thousand with autism
who utilize our free services!

In Honor:

In Honor of Jean Bushnick
Janice Nathan
Sam Bushnick
Myron Bushnick

In Honor of Tom Gray & Anne
McGinnis' Engagement
Leslie Marshall
Susan O. Smeragliuolo
Charitable Fund



Pitt Early Autism Study Objective?

- Our primary goal is to understand the earliest indicators of Autism Spectrum Disorder and uncover diagnostic signs that emerge within the first years of life.

Who we are Including?

- Infants who have an older sibling with ASD.
- Toddlers with ASD who are not yet speaking in complete sentences.
- Families should be local or willing to travel to Pittsburgh for testing.

What is Involved?

- Children will visit the University of Pittsburgh several times and will be recorded as they watch pictures and movies (e.g. Mr. Roger's Neighborhood).
- Assessments for Autism will be given at no cost. Compensation for completed studies.

Contact Information: www.pitt.edu/~infants
autismrecruiter@upmc.edu or (412) 246-5485

University of Pittsburgh



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
Lindsay Nickel, 412-624-4517
ICL@pitt.edu

USEFUL LINKS:

www.pitt.edu/~icl



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Pittsburgh, PA 15260



This research is supported by a grant from the National Institutes of Health.

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- * Therapeutic Social Groups
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- * Extended School Year Summer Programs

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What should I do if I think something is wrong?

ASK

www.aboard.org/answers

Available 24 hours a day, ABOARD's Autism Answers empowers you with the peace of mind you need and deserve.

Get the answers to your important questions and concerns about autism by having a conversation with a peer that truly understands your situation and has walked hundreds of miles in your shoes.

**Experience the connection. Experience the support.
Experience ABOARD. We Know!**

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ACADEMIC PRESCHOOL an academic and therapeutic program for children with autism, and their typical peers.

BHRS IN-HOME SERVICES (WRAPAROUND) using Applied Behavioral Analysis (Verbal Behavior) and Relational Therapy for treatment.

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The Scott E. Folmer Awards

In May 1972, The PARC Consent Decree mandated the Commonwealth, the Pennsylvania Department of Education, and PA Department of Public Welfare identify, evaluate, and educate all students, and establish due process procedures for students with disabilities. It also provided for the establishment of a state task force and 29 local task forces (one in each intermediate unit) whose primary purpose is to insure that the intent and spirit of the Right to Education Consent Agreement is carried out throughout the Commonwealth. *This was the beginnings of special education for the country!*

The Local Task Force on the Right to Education of Allegheny County (LTF #3) serves as a resource for children with all disabilities and their families in the forty-two school districts in Allegheny County. The LTF's role is to communicate needs and problems to the appropriate sources. On May 7, 2008, The LTF #3, the AIU and Carlynton School District sponsored The Scott E. Folmer Awards Ceremony.

Scott Folmer was a man who wore many different hats. The one he wore last and was most well known for was that of a proud grandfather. It was this hat that made him join the fight against autism. When his first grandchild was diagnosed with autism, he wept more than anyone in the family. However, within days of the diagnosis the battle began. Scott turned everywhere he could to become educated on this devastating epidemic. He joined committees, went to meetings, attended lectures and read anything he could about autism. Through all the differ-

ent outreach programs he encountered and the people involved, he found hope. Often, Scott would be heard saying, "I have no doubt that Caithlin is going to beat autism and live a great life." He was right; Caithlin is a successful fourth grader who enjoys swimming, tae kwon do, fashion, games and movies.



Scott died tragically in May of 2004 on his way home from work. This was a true family man who loved children. He worked everyday of his life out of love for his family and those around him. Although he is gone, his dedication to the fight against autism continues through his family and everyone he touched in his life. His wife, Cindy said, "I don't know where Caithlin would be today, if there had been no ABOARD, or task force to point the right direc-

tion for us. Caithlin is doing well, giving us new issues, which I hope we will still find the right way. Someone, and I don't remember who once told me autism is like an onion, you peel away the layers, only to find new ones."

The Scott E. Folmer Awards are given to a student who through a single act of courage or continued friendship has helped another student be an active and accepted member of the community.

Ian Kinser was the winner and Katie Kane won Honorable Mention.

An award is given to a school that has developed an exemplary practice to support the education of children receiving special education.

Penn Hills School District, Forbes Elementary won because of their successful Inclusive Education Week. South Park School District won Honorable Mention because of their successful Parent Mentoring Program.

An award is given to a professional who fosters and supports the education of students by establishing high expectations and recognizing that all students can learn.

Heidi Kohne, North Hills School District, Junior High won and Christine Botti, Hampton Township SD, High school won Honorable Mention.

Congratulations to the winners!

**Here's how to find
your
Local Task Force:**

**[http://
parent.pattan.net/
StateTaskForce/
ChairsCo-Chairs.aspx](http://parent.pattan.net/StateTaskForce/ChairsCo-Chairs.aspx)**

Autism Disaster Relief Effort

For Autism Families of the Mid-West Floods

The Autism Help Network, Inc. and ABOARD have teamed up together in this effort to help raise \$100,000 for Autism Families devastated by the Mid-West Flooding.

Our efforts are being used to purchase much needed supplies for children with autism such as:

- Biomedical Supplements
- GFCF Foods
- Therapy Tools
- Support Equipment

We Are Asking for Your Help in This Effort!

Visit:

www.autismhelpforyou.org

To Make Your Online Donation
Or Mail to:

AHN - 4714 Valleyfield Drive, Allison Park, PA 15101



All donations are tax
deductible

The Autism Help Network, Inc. is a
licensed 501 C 3 non-profit organization



ABOARD'S 2008/2009 Organization/Corporate Partnerships

Partnership with ABOARD is mutually beneficial. It supports our work in meeting the needs of Pennsylvanian families challenged with autism spectrum disorders. It also keeps your organization "front and center" in the minds of those very families. We will do this by acknowledging your membership in our quarterly newsletter as well as on our website, which is being re-designed. Also your organization will receive a discounted rate to exhibit at our conferences along with a 20% discounted registration fee when sending 5 or more of your employees to attend our conferences and workshops. Any organization interested in being an ABOARD partner, please complete the form below.

Thank you for your support:

The Alliance for Infants & Toddlers
Alliance Health Wraparound
Arc of Mercer County
Autism Speaks
The Children's Institute of Pittsburgh
Clearfield-Jefferson MH/MR Program
Comprehensive Children and Family
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Diversified Human Services, Inc.
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The Stern Center for Developmental
& Behavioral Health
Step by Step, Inc.
The Watson Institute
Westmoreland County MH/MR Program
WJS Psychological Associates, Inc.

2008/2009 ABOARD Membership Form

Organization/Corporate membership offering for the remainder of 2008 and all of 2009: \$250

Organization _____

Contact Name _____

Address _____

Phone # _____ Fax # _____ E-mail _____

Mail form with your check or credit card info. to: ABOARD

35 Wilson St., Suite 100, Pittsburgh, PA 15223

Credit Card (VISA, Master Card) _____ Card # _____

Name as it Appears on Card _____

Statement Billing Address _____

Expiration Date _____ Authorized Signature _____

Autism Awareness Day at PNC Park



Join the Pittsburgh Pirates, Autism Speaks, and Athletes Against Autism as we host a special day to raise awareness and recognize those affected by Autism within the region. Family and friends are encouraged to join us at this special event, which will be part of a large awareness effort to support their organizational objectives.

Sunday, July 27, 2008 - 1:35 p.m.

Pittsburgh Pirates vs. San Diego Padres

All children 12 and under receive Build-a-Bear Cheese Chester

Following the game - Kids Run The Bases

Pirates Cove - \$16.00 (Includes \$5.00 food credit)

L/R Grandstand - \$8.00 (Gate price 9.00)

- Show your autism community pride and bring the gang to the game!
- Groups of 20 or more will be seated together and receive recognition with the group name on the Color LED board during the game.
- Questions and ticket orders should be directed to Chaz Kellem in-order to receive special offer.



Autism Awareness Day Order Form

Name: _____
 Organization: _____
 Address: _____
 City: _____ State: _____ Zip: _____
 Phone: _____ Email: _____

Please send me:

_____ Pirates Cove @ \$16.00 per ticket = _____
 _____ L/R Grandstand @ \$8.00 per ticket = _____ Grand Total = _____

Shipping/Processing \$3.00 (per order)

Method of Payment: Visa MasterCard AMEX Discover

CC#: _____ Exp: _____ Check#: _____ (Made Payable to: Pittsburgh Pirates)

Please mail to:

Chaz Kellem
 Autism Awareness Day
 Pittsburgh Pirates
 115 Federal Street
 Pittsburgh, PA 15212

Phone - 412.325.4488 Fax - 412.325.4410
 Email - Chaz.kellem@pirates.com



SEE YOU AT THE GAME!

THANK YOU FROM ABOARD



On May 3 ABOARD participated in the 6th annual Walk for a Healthy Community presented by Highmark Blue Cross Blue Shield. We were one of 37 participating health and human service agencies who serve Southwestern PA communities. The walk took place at Heinz Field and although the weather didn't cooperate, the crowd was large and didn't seem to mind getting wet!

ABOARD would like to thank everyone who helped to make the walk a success. Over 200 people walked and helped to raise over \$19,000 to support our family service program. We appreciate all of your help and support!

Thank you to all our teams and team leaders that signed up to support ABOARD:

Crane	Sutter
Lee	Swaz
Nathan Frank	Dudash
Becca Boo (Suppo)	Charlene Fulton
Pitt Autism Study	Serina Burkhart
Angel Eyes (Erin Simpson)	Benedek
Cadence	Hasselbusch
Teens	Chelsea Smith
CH/CR (Beth Rom)	Simonetti
B-Team	FBR
Hezekiah's Helpers (Caro)	LEAP
Guthrie	Creighton
Partners for Quality (Tammy O'Brien)	Mozelewski
Team Luke (Cheryl Hartzel)	Schrank
Jen Fulton	Chelsea Smith

ABOARD was fortunate to receive an incentive prize donation of free salad coupons from McDonald's Corporation for our walkers. Diane Catterall along with her sister, Donna Enzerra, was instrumental in obtaining this generous donation. Thank you Diane and Donna for your ongoing support in making this happen!

Our wonderful walk day volunteers were Heather Plassio and Heather Harbert from Northwestern Human Services. Thank you for all your help to get our walks signed in!

Again, we thank you all for supporting ABOARD.

We could not continue to help families confronted with the challenges that autism presents without your continued support!

THANK YOU FROM ABOARD

Thank you to all our donors that helped support our walkers and teams!

Robert Aber	Kevin Crane	Jared Hoff	Michelle McKee	Charlotte Scholl
Tony Adams	Mark Cristallini	Jean Homer	Shannon McKenzie	Carolynn Schrading
Diane Adams	Lynne Curtis	Jeff Hudale	David McMaster	Jonathan Shank
Laurel Adelman	William Davis	Roy Huffman	Sandy McMeekin	Anna Shaw
Nancy Albinini	Gail Davis	Clara Jaeckel	Judith Mcnight Krynski	Benjamin Shelly
Albert Albinini	Katherine Davis-Flynn	Himani Jain	Cindy Meeder	Joseph Shumba
Barbara Albinini	John Dawson	Nichol Jameson	Alberta Meinert	Irene Sidel
Mom's Club of Allison Park/Glenshaw	Wayne & Regina Desbrow	Erica Jamieson	Dana Meissner	John Siegfried
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Karen Cenci	Janet Grinder	Aaron Lenchner	Patricia Petronio	Susan Voll
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Advisory Board on
Autism and Related
Disorders

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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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