



BCC-ASA News

*Baltimore-Chesapeake Chapter
of the Autism Society of America*

July 2007

*The purpose of this newsletter is to provide information regarding Autism, Asperger's Syndrome and related disorders.
We do not necessarily endorse the information printed in this newsletter.*

Calendar Close Up

July & August Support Group: The Place to Learn Super Summer Survival Tips

Yes, BCC-ASA meets all year round, so come join us on **July 5** and **August 2** for our regular support group. We will be sharing with each other suggestions to help with summer stressors. Come learn from others what has worked (and hasn't!) and come away with some new ideas. Join us for answers to your questions on a variety of subjects. As usual, light refreshments will be available.

September Support Group: The Impact of ASD on Siblings

Join us on **September 6** as we welcome our speaker, **Addison Beck, Coordinator of Sibshops**. Sibshops is a program just for brothers and sisters of kids with special needs; it is also a celebration of the many contributions made by brothers and sisters. Come hear what the children themselves have shared about the impact of having a brother or sister with special needs. Learn tips to help your child and support your family or any family with which you are involved. This meeting is open to all – parents, professionals, and the general public. This will be a very informative and powerful evening. We hope you can join us!

BCC-ASA's "Day at Camden Yards" Fundraiser Rescheduled

The Orioles-Kansas City Royals game postponed by rain on April 15 has been rescheduled for **Monday, Sept. 24 at 7:05 p.m.** Fans with tickets dated April 15 should use them on Sept. 24. In the event you cannot attend the make-up game, you can exchange your tickets for one of the remaining non-prime home games during the 2007 season. Call (888) 848-BIRD for more information.

Calendar

- July 5 BCC-ASA Support Group, 7:00 p.m., *Summer Survival Tips*
- July 10 Adult Autism Resource Group (AARG), Towson, 7:00 p.m.
- July 11 *Understanding temperament: Working with young children* Abilities Network, Towson, 10:00 a.m.
- July 17 Baltimore County ABA/Verbal Behavior Interest Group, Maiden Choice, MD, 7:00 p.m.(see www.bcc-asa.org/VBIG.pdf for details)
- July 18 *Time in: Understanding and preventing behavior issues* Abilities Network, Towson, 10:00 a.m.
- July 25 *Autism spectrum disorders: Sensory sensitivity* Abilities Network, Towson, 10:00 a.m.
- Aug. 2 BCC-ASA Support Group, 7:00 p.m., *More Summer Survival Tips*
- Aug. 21 Balto. Co. ABA/Verbal Behavior Interest Group, Maiden Choice, MD, 7:00 p.m.
- Sept. 6 BCC-ASA Support Group, Speaker: Addison Beck on *Siblings*, 7:00 p.m.
- Sept. 11 Adult Autism Resource Group (AARG), Towson, 7:00 p.m.
- Sept. 18 Balto. Co. ABA/Verbal Behavior Interest Group, Maiden Choice, MD, 7:00 p.m.
- Sept. 24 *Day at Camden Yards*, BCC-ASA Fundraiser (rescheduled from April 15)
- Oct. 20 *Walk Now for Autism*, The National Mall, Washington, D.C.
- Oct. 21 *Walk Now for Autism*, Towson University

The President's Communication by Heather Thoms-Chesley

Well, summer certainly is here! Those hot humid lazy days of summer. I know in my house it's the most challenging time of the year. Trying to organize activities to entertain the four children while school is out, helping Victoria adjust to ESY, and then the challenge of getting ready for the next school year in August. Plus, in July I will represent BCC-ASA at the Autism Society of America's National Conference in Phoenix, Arizona, where I will receive valuable leadership training and learn about the latest trends in Autism. Upcoming articles will share what I learn at the conference.

It is a busy time behind-the-scenes for the BCC-ASA board. Over the summer we start planning for the events of the fall and winter – keep your eyes open for new items that will appear in the newsletter as well as some exciting changes. The board is dedicated to being responsive to the membership and to reflecting the changing demands placed upon us by the community and the ever-growing numbers of individuals being diagnosed with an Autism Spectrum Disorder. The board is reviewing the surveys that have arrived. We still would like to hear from you if you did not get a chance to return your survey. The Partnership Project is aiming to hear from 5% of the families with children with ASD in the Baltimore County Public Schools and we are closing in on that figure. The surveys are available on our website and have been re-sent via email, if you are on our email list.

We welcome the new families who have joined our chapter from Baltimore City Public Schools, thanks to the efforts of Mrs. Gloria Price-Williams who spread the word about our support group within the City's parent network. We also welcome the new members who joined from the College of Notre Dame (see page 2 for details).

Together we will improve the lives of those affected by Autism. If you would like to volunteer some time, write a newsletter article, offer to help on a committee, volunteer to hand out our chapter information at a table, or other such activities, please contact our chapter at questions@bcc-asa.org or me directly at thoms-chesley@verizon.net or 410-882-2146. I look forward to seeing you at a future meeting or event.

Recent Donors to BCC-ASA

The chapter thanks all those who have recently sent us donations. The following donors sent contributions to BCC-ASA along with their dues renewals:

Matt & Annette Piatek
Laura Peitersen
Paige Pape
Mary Ellen & Bill Curtis
Greg & Michelle Wright
Barbara & Lewis Gorsuch
Linda & Larry Pearl
Chris & Ellen Feifarek
Paula & Rebecca Drinks
Alice Weisko, Psy.D.
Joseph Smith, Jr.
Luann & James Hughes
Mark & Leslie Osteen
Tom Hoglund & Barbara Martin

Additional Donors:

Charles Duffy
Frank Lanigan, Jr.
Audrey Leviton
Adrienne Gleason

We have received a donation from the **Jemicy School Outreach Center** in appreciation for a presentation given by **Dr. Eve Band** on Advocacy Day, April 14, 2007.

Charlotte Lerner has given a donation in honor of the **Bar Mitzvah of Adam Wolod**.

John Evans of the **Miller-Dippel Funeral Home** has given a donation in honor of **Charles Fowler, Jr.**

AARG! Summer Schedule

The Adult Autism Resource Group will meet as usual on Tuesday, July 10, from 7:00 to 9:00 p.m., but will not hold a meeting in August. The group will meet again on Tuesday, September 11.

Except for the break in August, this sub-group of the chapter meets the second Tuesday of every month at the home of Ellen Feifarek, 508 Hampton Lane, to work on issues that concern adults and transition-age youth with autism. Call Linda Pearl at 410-769-9500 during daytime hours if you plan to attend.

New Website for Spanish-Speaking Families

A new web site provides information in Spanish about Autism Spectrum Disorders. For more information, go to www.manitasporautismo.com.

The Resource Corner by Elisa Hartman, BCC-ASA Member

Welcome to the Resource Corner, a new feature where you can find useful and practical ideas to help you and your child.

At June's support group meeting, I mentioned two resources my children have enjoyed, both created by certified Music Therapists. The first is *My Turn, Your Turn, Songs for Building Social Skills*, by Cathy Bollinger. This CD has catchy tunes with titles like "I Can Say Excuse Me," "Can I Play Too?," "Who When What," and "It's OK That Sometimes I Don't Understand." These tunes are appealing and break down everyday interactions into simple patterns. This CD is available at www.rivannamusic.com for \$15.98, plus \$3.50 for shipping. There's a newer CD featured there that also looks great called *Ready to Learn, Songs for School Success*. The website features a Juke Box so you can listen to samples of the songs before buying.

Secondly, my seven- and two-year-old enjoy watching two DVDs produced by Spectrum Connections. They are part of the *Connecting through Music* series and follow a class taught by Music Therapist Elizabeth Balzano. The first DVD is called *Connecting Emotions* and the second, *Connecting Body Movement*. They are \$12.99 each and available from www.spectrumconnections.com, a company created by a mother of a child on the spectrum. Enjoy!

Tune in in September, when I will feature where to look for free legal assistance with educational problems (if your income is below a certain threshold).

Walk Now for Autism Set for October 21 in Baltimore Area

Cure Autism Now and Autism Speaks have merged and have combined WALK NOW and Walk For Autism Research into a single program. The Baltimore walk, to be held at Towson University, will be held on Sunday, October 21. In addition, the Washington DC walk is scheduled for Saturday, October 20 and will be held on the National Mall. Further information is available at www.autismwalk.org. You can register to walk as an individual, or form a team and create your own webpage. It's easy to do and puts the "fun" in fundraising!

The Radio, Women's Basketball and BCC-ASA

Hmmmm. What is the connection you ask? Well, here's the story: In April 2006, BCC-ASA members Annette Piatek and Ellen Feifarek were interviewed about Autism on WNST 1570-AM Sports Talk Radio. It turns out that the interview was prompted by the fact that Rob Long, host of his own weekday afternoon show on WNST, The Rob Long Show, is the father of a son with autism and an active promoter of Autism Awareness. He also coaches the College of Notre Dame of Maryland's Women's Basketball team (and very successfully we must add – they won the conference championship this year, Rob's first year at the school!). His team members, in order to honor their coach and join in his cause, have become members of BCC-ASA. We are honored to have the following new members from the College of Notre Dame of Maryland's Basketball team:

Casie Hall	Melissa Flora	Francis Lanigan, Jr.
Katie Lawson	Faith Wassink	Francis Lanigan III
Gloria Broady	Ashleigh (AJ) Johnson	Anthony Kratz
Latoya Broady	Dolores Hall	Ellen Kratz
Whitley Noel	Warren Hall	Donna Gastler

Board Member Receives Award

BCC-ASA is pleased to congratulate our own board member, **Hilary Hellerbach**. On May 2, the Arc of Baltimore held its Annual Meeting and Awards Ceremony. Hilary was honored for her dedication to individuals with disabilities by being awarded the 2007 Special Appreciation Award. This award is given to individuals who render truly outstanding assistance to the Arc of Baltimore and the people with developmental disabilities the Arc supports. Hilary has served on our board since 2005 and has facilitated a well-received support group meeting on the IEP process, written articles for our newsletter, helped the BCC-ASA-supported edition of *Hand-in-Hand* get processed, and offered her expertise to the board. Congratulations Hilary and thank you for supporting the Autism Community!!!

New Board Member Elected to Fill Vacant Seat

Board Member Shelley Kennedy has regrettably had to retire from our board. In June, the Board voted to have BCC-ASA member Tom Hoglund fill the vacancy. Tom, his wife, Barbara Martin, and their six-year old son Chad live and play in Baltimore. Tom is employed as a science writer at the National Institutes of Health in Bethesda, MD. When not commuting, he enjoys music, literature, film, cooking, and gardening. His son's enthusiasm for aviation and aerospace has allowed Tom to revisit his youth by flying radio-controlled airplanes and launching model rockets.

Chad was diagnosed with Asperger's syndrome in December 2006. Since learning just how special their child is, Tom and Barbara have been working to create a world for Chad that accepts and sometimes even celebrates his differences.

Autism has reached a turning point in its history. As society reconsiders autism, Tom would like to help influence the process. That effort is much larger than any one person and so by filling the board vacancy of the Baltimore ASA, he hopes to find strength in numbers on a 10 month trial basis.

Leisure Resources Newsletter Available

The Office of Therapeutic Recreation Resources of Baltimore County distributes a newsletter twice a year listing recreational opportunities specifically designed for individuals with disabilities, their families and friends. The publication, called *Leisure Resource* is available at www.baltimorecountyonline.info under "Recreation" in the Directory and then "Disabilities." If you don't have access to a computer, you may call 410-296-7667 for a copy.

Special Needs Cruise Scheduled for August

A 7-day cruise, leaving from Tampa, Florida, is available to families with a child with special needs. The website to visit for more information is: www.specialneedscruise.com.

CNN Video Posted on the Internet by Individual with ASD

For a very moving glimpse into the world of a person on the spectrum, visit www.cnn.com/2007/HEALTH/02/21/autism.amanda/index.html.

Family Empowerment Network Presentations

The Abilities Network's Family Empowerment Network will host a series of free presentations. The schedule for the presentations, which will all be held at the Abilities Network office on LaSalle Road in Towson, is as follows:

Wednesday July 11th from 10:00 am - 1:00 pm

"Understanding temperament: Working with young children"

The presentation will help participants define and understand temperament and its influence on personality development. Participants will learn how temperament is related to children's behavior and develop strategies for supporting children with various temperament types.

Wednesday July 18th from 10:00 am - 1:00 pm

"Time in: Understanding and preventing behavior issues"

The presentation will help participants understand reasons for behavior and possible motivators of behaviors. Participants will utilize tools to help in identifying the reason for the behavior and ways to prevent future issues, so that they can provide a nurturing environment. Participants will explore preventive strategies and how these affect children's behavior.

Wednesday July 25th from 10:00 am - 1:00 pm

"Autism spectrum disorders: Sensory sensitivity"

The presentation will help participants understanding sensory integration, sensory integration dysfunction, and how sensory issues can impact children with autism spectrum disorders. It will discuss ways to include 'sensory diets' and sensory activities that assist children with ASD in being successful in their environments.

Registration for each session is required by the Friday before each workshop. Childcare will not be provided. For further information or to register, contact Sarah Pinsker at (410) 828-7700, ext. 1259, or spinsker@abilitiesnetwork.org.

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Sign up now for ***Bccasanews*** and have your BCC-ASA newsletter delivered to your e-mail Inbox before it is printed and sent by US mail. Here's how to sign up:

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To unsubscribe to *Bccasanews*, send an email to Bccasanews-request@bcc-asa.org and, on the Subject line type: unsubscribe

Or you may visit <http://seven.pairlist.net/mailman/listinfo/bccasanews> and subscribe or unsubscribe there.

First Annual International NATTAP Conference

The Network of Autism Training and Technical Assistance Programs (NATTAP), and the Autism Society of America (ASA) present the First Annual International NATTAP Conference hosted by the Ohio Center for Autism and Low Incidence (OCALI) in Columbus, Ohio. The 2007 NATTAP Conference is scheduled for September 26-28 at the Greater Columbus Convention Center and will feature sessions on the following topics/themes & much more:

Training on National, State and Regional Levels
Structure and Support: Providing Successful College Programs for Students with ASD
Behavior (PBS and other Intervention Strategies) Assessment
Transition to Adulthood
Instructional Techniques

The First Annual International NATTAP Conference will gather parents and professionals from across all 50 states and over 15 countries. The objectives of the conference are to review current models of systems, best practice in research and intervention use and methods of capacity building – all of which contribute to the ultimate goal of improving outcomes for individuals ages 3-21. A forum will be provided in which ideas will be exchanged that will set a new foundation in autism spectrum disorders (ASD).

What Siblings Would Like Parents and Service Providers to Know

by Don Meyer

Director, Sibling Support Project of The Arc of the United States

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In the United States, there are over six million people who have special health, developmental, and mental health concerns. Most of these people have typically-developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

1. These brothers and sisters will be in the lives of family members with special needs longer than **anyone**. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
2. Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services will arrive when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. The Right to One’s Own Life. Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their *own* lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically-developing siblings may assume without a frank and open discussion. “Nothing about us without us” – a phrase popular with self-advocates who have disabilities – applies to siblings as well. Self-determination, after all, is for everyone – including brothers and sisters.

2. Acknowledging Siblings’ Concerns. Like parents, brothers and sisters will experience a wide array of often ambivalent emotions regarding the impact of their siblings’ special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings’ life-long and ever-changing concerns.

3. Expectations for Typically-Developing Siblings. Families need to set high expectations for all their children. However, some typically-developing brothers and sisters react to their siblings’ disability by setting unrealistically high expectations for themselves – and some feel they must somehow compensate for their siblings’ special needs. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

4. Expect Typical Behavior From Typically-Developing Siblings. Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters – even when one has special needs. While parents may be appalled at siblings’ harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, “Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise.” Typically-developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. Expectations for the Family Member with Special Needs. When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically-developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically-developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules – one for them, and another for their sibs who have special needs.

6. The Right to a Safe Environment. Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. Opportunities to Meet Peers. For most parents, the thought of “going it alone,” raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and SibKids, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters – like parents – like to know that they are not alone with their unique joys and concerns.

8. Opportunities to Obtain Information. Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling’s disability, and its treatment and implications. Parents *and* service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. Sibs' Concerns about the Future. Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitude toward the extent of their involvement as adults may change over time. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

10. Including Both Sons and Daughters. Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings – including brothers – should be considered.

11. Communication. While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. One-on-One time with Parents. Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. Celebrate Every Child's Achievements and Milestones. Over the years, we've met siblings whose parents did not attend their high school graduation – even when their children were valedictorians – because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. Parents' Perspective is More Important than the Actual Disability. Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

15. Include Siblings in the Definition of "Family." Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs – the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered" – instead of "parent-centered" – services.

16. Actively Reach Out to Brothers and Sisters. Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

17. Learn More About Life as a Sibling. Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

18. Create Local Programs Specifically for Brothers and Sisters. If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families. Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. Fund Services for Brothers and Sisters. No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone – longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact: Sibling Support Project of The Arc of the United States, Don Meyer, Director, 6512 23rd Ave NW #213, Seattle, WA 98117, 206-297-6368; e-mail donmeyer@siblingsupport.org or go to www.thearc.org/siblingsupport

Essay Contest Winners

Below are the final three 1st Place winning entries from BCC-ASA's "How has autism affected your life?" Essay Contest. In September we will publish the Honorable Mention winners.

Look Into My Eyes . . .

**by Roni Elizabeth Dinkes, Audiologist
Winner, Professionals Category**

Look into my eyes
The lights are on....
I am thinking, Dreaming, Laughing, Talking, Walking, Dancing, & Smiling....
Take a moment....
Look close....into my eyes....into my world
See what I see....
My eyes are my windows to my soul
Be quiet for a moment...listen to what I hear
I hear the beauty of the world....
I may not be able to talk or write....
In a way you understand.....
But I can communicate
You just need to listen to me
Watch me.....
Follow me....
Just give me chance to fly
Spread my wings....
Chance to live....
Achieve my goals...
My hearts desires....
Chance to strive to be the best I can be....
Chance to dream.....
Chance to learn....
Take a chance on me....listen to me....
I have a lot to say....
A lot to contribute....
I promise you will learn more from me....
Than I will ever learn from you.

Mommy

by Charles Duffy

**In Honor of His Grandson, Curtis
Winner, Grandparents Category**

Mommy, I want to say I love you,
But I really don't know how.
I open my mouth to speak,
But only noises come out now.
I shake my hands to show you
The words I want you to hear.
I hope you're able to see
I love my Mother, dear.

Because My Child Has Autism . . .

**by Kelly Jednorski
Winner, Parents Category**

Because I have a child with autism,
I learned How to cut hair on a moving target;
I learned How to grocery shop one handed;
I learned How to REALLY lock cabinet doors.
Because my son has autism,
I learned How to touch without using my fingers;
I learned How to talk with my hands;
I learned How to listen with my eyes.
Because Sparky has autism,
I learned How to be a lot more patient and a little less demanding
I learned How to hear "I love you Mommy" from a smile;
I learned How to love unconditionally, completely . . .
Because I have a child with autism.

NEW BOOKS IN THE BCC-ASA LIBRARY

by Elaine Williams, BCC-ASA Librarian

With so many excellent publications coming out about autism and related disorders, we're pleased to have added the following resources. This is a only partial list; more reviews will appear in the September newsletter. Members of our chapter whose dues are up-to-date are welcome to take one book at a time from our library, which is open during support group meetings. These are great books! They offer terrific ideas and insights as you work with your family members who have autism.

A Novel

There are few novels featuring a family with autism, and Marti Lembach's portrayal of a mother facing considerable hardships in her story ***Daniel Isn't Talking*** is a loving and hopeful story of parental devotion.

Autism – General

Edward Ritvo has summarized his 40 years of clinical practice and pioneering research on autism in the book ***Understanding the Nature of Autism and Asperger's Disorder***. Dr. Ritvo is an internationally recognized medical expert in the field of autism, who explains the basic nature of autism, what's different in the brain, and treatments that work (and those that don't), based on his lifetime career experience.

Biography

In his ***Letters to Sam: A grandfather's lessons on love, loss, and the gifts of life***, Dan Gottlieb has given us a collection of 32 intimate and compassionate letters to his grandson, who has autism. Dan himself has been paralyzed from the neck down since an automobile accident 25 years ago, and he brings a large measure of soul-searching in a deeply touching book that can help us all learn to live richer, more satisfying lives. This is an especially good book to share with family members and friends.

Voices from the Spectrum, edited by Cindy Ariel and Robert Naseef, is a collection of first-hand accounts of the autistic spectrum by parents, grandparents, siblings, persons with autism, and professionals. It gives a rare and heartfelt glimpse of the personal journeys of persons affected by autism which offers a range of perspectives, emotions and coping mechanisms, teaching us how autism feels to each of these observers.

Sarah Stup is a young woman from Frederick, MD, whose writings are real treasures of sensitivity, humor, and understanding. ***Are Your Eyes Listening*** is a book of poems and prose, including the poignant observation: "*Because of autism, the thief of politeness and friendship, I have no sounding voice. By typing words I can play with my life and stretch from my world to yours.*"

Send in the Idiots, by Kamran Nazeer, takes its name from a phrase repeated by one of his classmates in a small school for children with autism in New York. Now, 20 years later, he revisits his schoolmates to find out how they're doing, and what it means to grow up with autism. It's a fascinating, candid, surprising, and moving tale of their lives.

Activities

Karen Levine & Naomi Chedd have come up with ***Replays***, a creative resource that addresses the challenging behaviors of children with autism spectrum disorders through interactive symbolic play, using a technique called Replays. It's an easy and fun tool that provides numerous step-by-step examples to guide children toward mastering their emotional and behavioral responses.

Children's Books

Everybody is Different, by Fiona Bleach, is a book for young people who have brothers or sisters with autism. As well as explaining the characteristics of autism in clear terms, it is full of helpful suggestions for making family life more comfortable for everyone concerned.

The Autism Acceptance Book, by Ellen Sabin, is a workbook with activities meant to be completed by children (we suggest that members copy the relevant pages) which helps to develop an understanding and empathy for those facing the challenge of autism.

Marvie Ellis has written a children's story about autism ***Tacos Anyone?/Alguien quiere tacos?*** about a boy with autism and his brother. The therapist teaches Thomas how to play with his autistic brother, Michael, making sibling time fun again. Part of the fun of this book, in addition to the illustrations, is that it's written bilingually, in English and Spanish.

Educational Strategies – Teaching

Marie Howley & Eileen Arnold have filled a need by providing a book of Social Stories with numerous case examples, including for adolescents and adults, titled ***Revealing the Hidden Social Code***. Endorsed by Carol Gray, originator of Social Stories, it is an authoritative guide to using this key technique for helping people with autism to understand and become familiar with social and life skills.

Incentives for Change, by Lara Delmolino and Sandra Harris, is a guide that provides parents and professionals with invaluable tools to help them with the often-challenging task of *motivating* children and adults with autism spectrum disorders. Topics include the use of incentives/reinforcers, and encouraging independence and self-management skills.

Many children and adults with autism spectrum disorders have great difficulty understanding and communicating with speech. Dr. Joanne Cafiero's book, ***Meaningful Exchanges for People with Autism***, is an excellent introduction to the techniques of augmentative and alternative communication, which provide the means for nonverbal persons to communicate in all life settings.

Baltimore County Adopts New IEP Format Effective July 1

by Heather Thoms-Chesley, BCC-ASA President

At the June meeting of SECAC (Special Education Citizen's Advisory Council), the new IEP format was discussed. PJ Shafer and Heather Thoms-Chesley have regularly attended these monthly meetings during the past school year to ensure that the Autism Community has a presence and a voice within the Council.

This new IEP format is a Statewide mandate effective July 1, 2007. Every county in the state of Maryland will be using this same web-based IEP format. BCPS's Student Data Office and the Office of Special Education have integrated the State-mandated format into the Tienet (web-based) IEP. This will allow consistency of delivery models, services provided and paper trails if families move from one county to another within the state of Maryland. Additionally, it will improve accuracy in the state's data collection system.

This April and May, the Office of Special Education staff and "trial" school participants were trained. In May and June, IEP team chairs were charged with the responsibility of training all IEP team members. Then, schools began to "pilot" the new state format on Tienet in order to troubleshoot any problem areas. There were several schools that were pilots for this new program. Harford Hills Elementary, where my 3-year-old son attends, was one of them. His IEP (for articulation only – no ASD issues) utilized this new format, which I found to be more exact than previous versions. In addition, it allowed for a quicker team meeting (a much-appreciated benefit). I'll warn you, though, that there will be much more paper to keep in your files – so make space now! Even my son's simple, straightforward IEP for speech services was 14 pages long! For some families with more complicated IEP's, the change will be quite noticeable. One of the major changes that Baltimore County families will observe is that Special Considerations and Accommodations will be discussed BEFORE the goals are created. This is a shift for BCPS which, until now, had first set the goals and then made special considerations and accommodations. A second noticeable change will be that the progress report information will be written directly on the IEP pages, via the web-based system.

Information about this change will be given to parents at their annual IEP review team. Suggested opportunities for additional parent-training sessions include at a SECAC meeting in the fall and at parent workshops coordinated by the Parent Resource Center. *And* through your BCC-ASA newsletter!!!! *Aren't you clever to be reading it already!*

From the National Office of ASA: Results of CDC Studies on Autism Prevalence Released

The Autism Society of America (ASA) welcomed the new CDC studies on the prevalence numbers of autism spectrum disorder (ASD) in the United States as tremendously significant data that will help the cause of improving the lives of all those affected by autism. In data collected from its Autism and Developmental Disabilities Monitoring Network (ADDM), a population-based, multi-state surveillance network that surveyed 8 year olds in 2000 and 2002, the CDC found that the data confirm that ASD prevalence affects approximately an average of 1 child in every 150. The data represents 10 percent of the U.S. population of 8 year old children.

ASA believes the CDC numbers are tremendously significant. "Finally, we can end the debate on the prevalence of autism in our nation and focus on getting the services and supports the families need," said Lee Grossman, ASA president and CEO. "Autism is a treatable lifelong condition that affects tens of millions of Americans today. It is time to aggressively address this national health crisis." The CDC is recommending public health actions to improve early identification of ASD.

The CDC study includes children with behaviors consistent with autism, Asperger's and pervasive developmental delays not otherwise specified (PDD-NOS). The data came from 14 sites in five states (Arizona, Georgia, Maryland, New Jersey, South Carolina and West Virginia). The study also found higher prevalence in boys than girls (a range of 2.8-6 boys to girls, depending on the state) and no statistically significant difference among non-Hispanic whites and non-Hispanic black children.

Colleen Boyle of the CDC noted that the study showed the age of diagnosis (at between 4-5 years of age) was much later than the age at which developmental concern was registered (before 24 months), underscoring the need for earlier identification of autism.

To read the study in full, please visit www.cdc.gov/autism.

A Guide for Transition to Adulthood

The Organization for Autism Research (OAR) has a new publication in their Life Journey through Autism series entitled *A Guide for Transition to Adulthood*. The guide provides information for parents, teachers, and professionals to help an individual with an autism spectrum disorder make the transition from adolescence to adulthood, including transition agencies and legal help, transition planning, vocation and employment, postsecondary education, and life skills. For a copy, go to www.researchautism.org/resources/reading/index.asp or call (866) 366-9710.

BCC-ASA Presentation at BCPS School Board Meeting

BCC-ASA members PJ Shafer and Elisa Hartman made a presentation to the BCPS school board on April 24, representing BCC-ASA and the Partnership Project with BCPS. Krystal Roach, the 1st place essay contest winner in the middle school category, read her essay about her younger brother with autism which generated spontaneous applause when she finished. She brought her parents and brother with her as well, which expanded the awareness among audience members even more.

PJ was chosen to speak after the regular board business as part of the public comment section. He told the board that April was Autism Awareness month, explained autism's core deficits, told them about the current finding that 1 out of 150 children is on the spectrum, reported that congress this past year has approved money for research, and highlighted the partnership's accomplishments. He also thanked Dr. Hairston for his time with SECAC and recognized Sara Egorin-Hooper for her endless work on behalf of children on the spectrum. He closed with asking that the school board increase professional development for principals, teachers, and all staff in how it relates to children on the spectrum.

Thank you PJ and Elisa on behalf of BCC-ASA. You really got the word out to those who can make a difference!

Educate Toward Recovery: Turning the Tables on Autism

Written by Robert Schramm MA, BCBA (Pro-ABA, 2006)

Review by Wil Gehne

Parents can find many useful resources to learn about how Applied Behavior Analysis using Verbal Behavior (ABA/VB) can help teach their children with autism. But many of these resources are written by professionals for professionals. Often a layer of unfamiliar terminology stands between parents and the practical information they seek. A plain language book intended for parents about ABA/VB has been needed for some time. Now Robert Schramm, a Board Certified Behavior Analyst who heads a leading autism intervention program in Germany, has met the need.

His title certainly catches attention. "Recovery" can be a controversial term, stirring up powerful feelings both of hope and of skepticism. Schramm speaks of recovery in the most common sense way I have found. He notes that autism is a descriptive, external label and so recovery

"does not mean that this child is somehow a better or more complete person than he was before the label was removed.

It also does not mean that the cause of the autism has been mysteriously eradicated. It merely means that as a team of caring supporters, we have found a way to educate this child to the point that the doctors have stopped calling him names."

Other terms in Schramm's title suggest more practical ways of thinking about how to help our kids. The idea of education *toward* recovery is very useful. The focus throughout the book is the idea that anything that moves the learner toward interaction also moves them toward recovery long term. Schramm uses this idea to explain why good ABA in general, and ABA/VB in particular, chooses certain techniques.

Delivering lots of positive reinforcement (delivering rewards) and when necessary using response cost (taking away desired items) and extinction (planned ignoring of behavior) are the techniques of choice because they keep the child focused *toward* interaction with us – keeps them wanting more of what we have to give. Similarly, this explains why negative reinforcement (rewarding with escape from interaction) or punishments must be avoided – they propel the child to run away from us and from recovery in turn. This is an insight that helps me think about our daily choices in our ABA/VB home program.

The idea of turning the tables is also powerful. Schramm points to ways we can use characteristics of autism itself to promote the education process. Kids with autism may tend to echo – so he explains how echoic transfer procedures can be the doorway into teaching functional communication. Kids with autism often stim – so he shows how we can use the powerful reinforcing value of those stim behaviors as motivation to perform learning tasks. In seeing opportunities where it would be easy to see just deficits, this book provides both a hopeful outlook and, more importantly, concrete advice toward realizing the hope through ABA/VB interventions.

This book is no replacement for Sundberg and Partington's 1998 *Teaching Language to Children with Autism or Other Developmental Disabilities* – the original sourcebook of ABA/VB. It is a useful companion to it. It is good to now have a parent-friendly book on the subject available. Luckily, we now have two: Mary Barbera and Tracy Rasmussen's *The Verbal Behavior Approach: How to Teach Children With Autism and Related Disorders* came out May 15.

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Support Group Meeting

The next support group meeting will be **Thursday, July 5** at 7:00 p.m. at Mount Washington Pediatric Hospital. The support group meets on the **first Thursday** of every month.

Directions to Mt. Washington Pediatric Hospital:

From North of Baltimore:

Take the Beltway (I-695) to the Jones Falls Expressway (I-83) south. From I-83, take the Northern Parkway exit, 10B West. Make a right turn off the exit ramp and make an immediate right turn onto West Rogers Ave. (the first street off the exit ramp). Go north on West Rogers Ave.; the hospital is on the right.

From Baltimore and South:

Take the Jones Falls Expressway (I-83) north to the second Northern Parkway exit, 10B West. Turn right onto West Rogers Ave. (the first street off the exit ramp). Go north on West Rogers Ave.; the hospital is on the right.

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