



CT Autism Spectrum Resource Center, Inc.

# ASRC Network

July 2008

## IN THIS ISSUE

Banishing The Babysitting Blues .....	2
To Tell or Not To Tell .....	4
Pat's Corner .....	10
Announcements .....	17

---

**CT AUTISM SPECTRUM  
RESOURCE CENTER (ASRC)**

101 No. Plains Industrial Road  
 Harvest Park, Building 1A  
 Wallingford, CT 06492  
 Phone: (203) 265-7717  
 Fax: (203) 265-7768  
[www.ct-asrc.org](http://www.ct-asrc.org)  
 Email: ct-asrc@sbcglobal.net

July 2008 • vol 3

**Dear Readers,**

It's official, **SUMMER IS HERE!!**

The ASRC would like to thank all of the supporters who joined us for our **10<sup>th</sup> Annual Walk For Autism** and our **2<sup>nd</sup> Annual Run For Autism!** We are happy to announce that we raised over \$150,000 during our event to help fund our programs for the coming year! These programs include training workshops, courses for professionals, first responder training, support groups, recreational programs, advocacy training series and our newsletter. It was a blessing that the rain held off and it was great to see so many of our family and friends join us at Choate Rosemary Hall. We hope to see you again next year!

On April 2<sup>nd</sup> the ASRC was at the Capitol in Hartford for our 3<sup>rd</sup> **Annual Autism Awareness Day**. Thank you to those who were able to join us in Hartford for our breakfast and press conference with Speaker of the House, Jim Amann and UCONN coach, Jim Calhoun.

The staff at the ASRC have been hard at work preparing summer activities for our younger children and teens. Be sure to check your e-mail every Thursday for the "ASRC Weekly Update." Included in our weekly e-mail are upcoming events, activities and announcements for our families and professionals. If you have not been receiving this weekly e-mail, please contact the office at 203-265-7717 to verify your current e-mail address with us.

### MEMBERS DID YOU KNOW

Members of the ASRC can log into their personal profile by visiting our website at [www.ct-asrc.org](http://www.ct-asrc.org) and entering their user ID and password. If you have any questions, including your user ID & password, please contact Pat Coppola at 203-265-7717.

Enjoy the rest of your summer and remember.....the kids will be back to school before you know it!

Jeanine DeLucia  
 Editor



# Banishing The Babysitting Blues

by Jean Stern, AANE Director of Children's Services

*Editor's note: The opinions expressed herein are those of the author exclusively.*

Parenting children with AS can be a joyous, rewarding and eye-opening experience. It can also be challenging, and at times exhausting. We all need breaks in our parenting hours to rest, refuel, and regenerate ourselves. For most families, that means hiring a babysitter – but where do you find one, and how can you help to ensure that the experience will go well? Here are a few thoughts.

## Where to look?

Some younger children may be able to be cared for by a responsible local teen, especially one who might be an older sibling of a special needs child. Ask friends, neighbors, or church or temple members for recommendations. You might ask the high school's social outreach coordinator if there are students who want to earn social service hours (now important for college applications). However, some of our children will need older, more mature sitters. As an educator I have found these options worth looking into:

- Contact your town's special education office and ask if you could post an ad for para-professionals to pick up some after-school, weekend or summer hours. Write a clear job description with the amount you can pay, what services you would like, what specific hours you are seeking, and any specific other details such as whether a car will be needed. Here is an example:

### Seek special sitter for special six year old girl

- 3 hours/week on Saturday mornings starting in April.
- Sitter can follow the easy schedule provided by parent.
- Pay is \$15 per hour.
- Please provide your own car
- For more information please contact (list your contact information).

- All towns also belong to educational collaboratives, whose classrooms use para-professionals as well.
- Colleges may also be a source of more mature sitters, possibly including students who have a particular interest in special education, psychology or social work. BU, Lesley, and Simmons offer special needs programs that specifically address AS. Students often look for flexible hours to fit around their class schedules. They may be looking for a job that can also offer them experience in the field they are going into; a letter of recommendation from a parent might be a welcome addition to a student's file. Sometimes a parent can even work with the student and a professor to enable the student to gain credit for an independent study designed around the specific care they give your child.
- AANE members can post that job description on the online parent support group. Some parents may be willing to share their prized sitters if they know that you are only looking for specific, limited hours.
- You can try: [www.collegehelpers.com](http://www.collegehelpers.com) (\$10 fee to advertise) or [www.sittercity.com](http://www.sittercity.com) which can be more expensive to use.

## Getting off on the right foot

Write out a few interview questions that you can use for each initial phone interview, once you start getting responses, e.g.:

- When are you available to sit?
- What experience do you have sitting other children?
- If they are classroom aides, “What children have you enjoyed working with?”
- For a student, “What interests are you pursuing, or what career you are heading toward?”
- Would you feel comfortable with following my child’s usual routine (simple playing, reading, bathing, etc.)?
- Be sure to ask for and contact references!
- Briefly describe your child and what s/he is comfortable with, and ask the sitter for thoughts about working with the child. Listen to the potential sitter’s answers to these open-ended questions, and ask follow-up questions as needed. Always listen to your gut feelings about a conversation. If it just doesn’t feel right, move to another person.

If you feel good about this person based on the phone interview, schedule a face-to-face interview, which might include the person spending some time getting to know your child while you stay in the house. Set **clear expectations** from the start, such as:

- Let the person know best strategies for a smooth interaction with your child, and how to handle any behavior problems. Explain the child’s Asperger Syndrome in concrete ways, letting the sitter know what s/he likes and dislikes (e.g. light touching, loud voice).
- Ask the sitter to avoid making or receiving personal calls while working.
- Show the person around the house, indicating where to find cooking implements, how to work the DVD player, etc.
- Post written house rules, and a written schedule (possibly with pictures). Include all necessary contact information and the time you will return.
  - Ask the sitter to stick to it because it makes the

child more calm and comfortable.

- Review when and how payment will be made.
- Remember to be very respectful of the person’s time, schedule, and needs. Consult the person to discuss any changes you might like to make, and express your appreciation. A little pampering may go a long way!

Hopefully these leads can help you find an excellent, reliable sitter, who will enrich your child’s life and also afford you some time to yourself or with a spouse or partner. If you know your sitter will be coming on a regular basis, you can plan ahead to do some of those things you need to do before you became a parent – remember those days?--and look forward to those adult activities. Then you will return to your parenting duties with new energy and a fresh perspective. Enjoy!

Babysitter Notes

Our address \_\_\_\_\_

Phone number \_\_\_\_\_

Will be at \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Mobile \_\_\_\_\_

Bedtime \_\_\_\_\_ TV \_\_\_\_\_

Meals/Snacks \_\_\_\_\_

Medicine \_\_\_\_\_

Allergies \_\_\_\_\_

Neighbor \_\_\_\_\_

Phone \_\_\_\_\_

Notes \_\_\_\_\_

Expect to be home \_\_\_\_\_



## To Tell or Not to Tell

By Nick Dubin

*Editor's note: The opinions expressed herein are those of the author exclusively.*

I cannot count the number of times I have been asked (or heard others asked) whether or not parents should tell their child that he or she has Asperger Syndrome. I will give my opinion in a moment, but first I want to address how this is relative to empowering victims.

*Tim and Ted are children with Asperger Syndrome, both 14 years old. They don't know each other, but they live only a few miles apart. They were both diagnosed with Asperger's at age 12 and are often bullied at school. The main difference between them is that Tim's parents have decided not to tell him he has Asperger's while Ted's parents have told him. Every day when Tim is bullied, he internalizes it and blames himself. He knows something is different about him but he can't put his finger on it. This sense of always wondering why he is different creates depression. Ted is also depressed. His parents told him that he has Asperger Syndrome, and he thinks it's a death sentence. He rationalizes that others bully him because he has a "disease" that makes him repellent to the other children.*

Playing devil's advocate, I have given two entirely different arguments why it is not good either to withhold a diagnosis or to disclose it. In my professional life, I have met practitioners who strongly advocate for disclosure as well as those who are vehemently against it. One can argue reasonably either way. Withholding the diagnosis can cause much confusion and

turmoil. When episodes of bullying take place, Asperger children know they are different but the lack of any real understanding can create a negative self-image. On the other hand, sharing the diagnosis may label the child as "defective," and he or she could become even more depressed after receiving that information.

However, Asperger Syndrome is nothing to be ashamed of. It is not a death sentence, nor is it a character defect. The fact is that Asperger Syndrome is a neurobiological difference. It results in perceiving the world through a slightly different lens than others. Many people have speculated that Thomas Jefferson and other notable geniuses may have had Asperger's. There is no shortage of brilliance among the population (Ledgin 2002). Along with this brilliance and uniqueness come differences from the general population. Unfortunately, those who have differences (or stick out in a crowd) are usually the ones who suffer the most from peer abuse while growing up.

Of course not everybody with Asperger Syndrome is a genius, but most people with Asperger's who I've met have some kind of unique personality traits, interests, or talents. Gail Hawkins (2004) states that these unique qualities have led to some of the greatest contributions to society. Gillberg (2002), a noted author on autism, agrees that people with Asperger Syndrome are a tremendous asset to the world. And yet, these same individuals are the ones who often suffer the

most peer abuse in childhood, simply because they are different.

Children have a right to know that their differences actually have a name. The name does not define their entire being but it does serve to provide some additional information for self-knowledge. While many children resist being diagnosed and may not even want to talk about it, these same children could continue to suffer from confusion and depression simply because they don't understand that their differences come from a group of traits that they were born with.

If parents withhold the diagnosis from their child, they should expect that eventually their child will discover this truth later in life. People generally need to acquire self-understanding in order to gain greater self-acceptance. The diagnosis of Asperger's can be the information that helps to accomplish this objective. If a child is not told about this diagnosis, a reasonable assumption the can make when learning of the diagnosis later in life is that there is something wrong with having Asperger's. For example, if I were diagnosed at age 12 but didn't learn about my diagnosis until adulthood, I would wonder why my parents withheld this information from me. Was there something bad about having Asperger Syndrome that my parents didn't want me to know?

By disclosing the diagnosis to your child, you are letting him or her know that Asperger's is nothing to be ashamed of. You are taking away the confusion and pain of not knowing the answer to the age-old question, "Why me?" Instead, you are empowering your child with the knowledge that being a little different could be the greatest gift the Asperger child can have. As my friend Michael John Carley, president of the Global and Regional Asperger Syndrome Partnership (GRASP), has stated, even if he were given the option to become a neurotypical, he would refuse to take it. He likes being different.

## ***About The Author***



*Nick Dubin is currently pursuing a doctoral degree at the Michigan School of Professional Psychology. He has produced DVDs on AS and is the author of the following books, published by JKP and available through the AANE web site:*

***Asperger Syndrome and Bullying: Strategies and Solutions*** (from which this article was excerpted)

***Asperger Syndrome and Employment: A Personal Guide to Succeeding at Work***  
***Breaking through Hidden Barriers***

### ***References:***

*Gillberg, C., A Guide to Asperger Syndrome, Cambridge University Press, 2002*

*Ledgin, Norm, Asperger's and Self-Esteem: Insight and Hope through Famous Role Models, Future Horizons, 2002*

*The following was written by one of the young ladies, age 12, who attends our Girl's Sibling Support Group.*



### **Why I Love & Look Forward to Sib Group**

The reason I love sib group and look forward to it is because I have so much fun playing all the games they prepare for us. Also you get to make friends with kids that are dealing with what you have to deal with. Another thing is this group helps me get closer to my brother. It helps me because you hear that other kids are going through the same thing as yourself.

### **Things We Do There**

During our first visit we start with a ball and throw it to someone and we say that person's name. This helps get to know the people in our group. Then when you do that you start adding more and more balls and they go everywhere! It is so much fun! Also we play a lot of other cool games, eat snacks and at the end of each group we do a crazy handshake that we made up. IT'S SO MUCH FUN THERE!

## **Fall Sibling Support Group**

The *girls* sibling support group will resume in the fall. Registration is required and space is limited. For more information regarding this valuable program, please contact Monica Trischitti at 203-265-7717.

*"A sibling in a friend given by nature"*

*~anonymous*



# READ ALL ABOUT IT

Girls Under the Umbrella of Autism Spectrum Disorders

**Practical Solutions for Addressing Everyday Challenges**

By Dr. Lori Ernsperger & Danielle Wendel

Reviewed by Maureen Bennie, Director of the Autism Awareness Centre Inc

There is an abundance of literature available on a variety of topics about autism spectrum disorder (ASD); however, most of these materials are written with males in mind since they comprise most of population Diagnosed with ASD. There are some excellent personal perspective Stories written by women on the spectrum such as DR. Temple Grandin, Donna Williams, and Liane Willey, but there are almost no books written about working or living with females with ASD. *Girls under the Umbrella of Autism Spectrum Disorders* fills this gap well by highlighting Issues for females from the early years to young adulthood. Author Dr. Lori Ernsperger, , an autism and behavioral specialist, provides the issues And strategies information while mother Danielle Wendell gives us the Important parent perspective and what parents experience on the life Journey of raising a daughter.

The ratio of boys to girls with ASD is 4:1; it is as high as 10:1 for Asperger Syndrome. Little is known about gender differences in ASD yet Observable differences exist. Most diagnostic and assessment tools were developed by observing traits in males. Girls on the spectrum present more subtly and therefore, can go undetected. My daughter Julia, who has autism, does not exhibit the same characteristics as my son Marc who has the same diagnosis. Julia is soft-spoken, does not engage in self-stimulatory behavior, has strong imaginative play skills, and is not aggressive. She can be ignored at school because of her compliant behavior whereas my son will get more assistance due to being more overt with his behavior.

For parents of daughter, the ASD journey can be a more isolating experience because there are fewer girls on the spectrum, making it difficult to meet other parents in the same boat. One of the strengths of this book is hearing from other mothers and their experience of raising a daughter. The candid re-telling of trying situations and feelings around ASD make you feel like you are listening to a good friend. Girls with ASD From elementary age to adulthood also speak about their lives-childhood Memories, school and community experiences, and frustrations. Hearing their stories provides perspective and insight for both parents and professionals.

*Girls under the Umbrella of Autism Spectrum Disorders* introduces you to who are the girls with ASD, the early years, school years, adolescence, early adulthood, and finally what the future my hold. Each chapter is broken down into manageable sub-topics supported by charts, lists, and important points to remember. A summary of the main thoughts ends each chapter.

The overview of the early years to early adulthood experience Guides parents and professionals through the myriad of issues and Concerns one will encounter. The Early Years chapter covers sleep problems, toileting, eating habits, and problematic behavior. The behavioral strategies are sensible and supported by the appropriate literature.

The School Years discusses IEP's social skills, emotions the OT and speech therapy portfolio, sensory processing disorder and tips for starting the school year. Bullying, a topic often overlooked in other ASD books, is touched upon. The Adolescence/Early Adulthood chapter focuses on self-determination, dating, transition planning, work and college.

The reference section of the book lists some of the best books and Articles on topics covered within this book. The appendix contains great Websites, a behavioral plan template, a positive environment checklist, and Social skills objectives.

This book will aid in effective advocacy for girls on the spectrum who don't present like their make counterparts and often slip through the Diagnostic cracks. One of the many strengths of this book lies with the Women who speak about their life experiences so candidly. *Girls Under The Umbrella of autism Spectrum Disorders* is essential reading for anyone who needs to understand females with ASD. As a mother of an 8 Year old daughter, this book was an eye opener and has given me Direction, support and new ideas on how to best help my daughter on this Journey.

Available for 27.95 from the Autism Awareness Center on-line or by  
calling Maureen Bennie at (403) 640-2710 in Calgary, fax (403) 451-9011,

---

## TURNING FAILURE INTO SUCCESS IN THE FOURTH DIMENSION

By Dan Coulter

*Editor's note: The opinions expressed herein are those of the author exclusively*

Ever gotten frustrated when you've failed? I have. It's especially hard when you feel that you're somehow failing as a parent—or that your child is failing at something and you can't fix the problem.

If you're trying hard and you've made repeated attempts, it can be especially disheartening.

But even this kind of failure can be a step toward success.

To illustrate, let's look at the movie, "Back to the Future." Marty McFly, the time-traveling lead character, is a young musician who won't send his audition tape to a record company because he's afraid of failure. During the film, Marty is continually admonished by time machine inventor Doc Brown, "You're not thinking fourth dimensionally!" By that, he means Marty isn't taking the affects of time into account.

What does time and thinking fourth dimensionally have to do with failure and success?

Failure can feel final in the moment when you experience it. But it's really only final for that moment. The next moment, you can start looking for another way to succeed.

In the film, Doc Brown has a framed photo of Thomas Edison over his fireplace. Edison tried thousands of experiments that failed before finding a good filament for the first practical electric light bulb. The inventor said of these failures, "They taught something that I didn't know. They taught me what direction to move in."

So, we just have to get into that mindset, right? Simple. Okay, not simple. But possible.

Late in the movie, we learn that Marty has what it takes to be a successful musician when he plays a knock-em-dead version of Johnny B. Goode on the guitar at a high school dance. This means, like almost all other good musicians, Marty had learned to practice through his initial failures to play songs adeptly, gradually becoming better.

Just like off-key notes are part of learning to play a piano or guitar, failure is part of the process in raising children. And no matter how experienced you get, no one gets it perfect.

My kids are 23 and 24 years old. They're both doing well. But I still have moments when I wish I could convince each to do things differently—and fail. But I'm much less likely to let frustration hamper me than I used to be. *(continued)*

---

I've learned to be more strategic, and try less direct approaches.

For example, when you encounter a behavior you want to change, biting your tongue and not commenting may be the best way to start the change process manners.

Let's say you're at dinner with your family and your daughter is taking large bites of food and talking with her mouth full. It's tempting to correct her then and there. But if you've tried that before and it just caused an emotional scene, maybe it's better to let it go for the moment. Then, plan a session where you sit with her and talk about it. Be inventive. Who are her favorite movie stars? Maybe you could find a movie that involves one of them sitting at a dinner table eating with good manners. Show her that section of the video and practice eating a meal with just you and her. Describe how you are both going to eat beforehand, demonstrate doing it right, then let her try. Make it fun. Don't expect too great a change in one session. Eat a number of private, practice meals. Talk about the benefits of eating politely. Praise progress.

Generating even a small success can help your child feel, well, successful. And success is a great building block to more success. Especially if you take on behaviors you want to change one at a time.

At the end of the movie, Marty (having traveled to the past, overcome numerous failures, and helped his father find new ways to succeed) returns to the future to find things changed for the better. He also finds a new optimism.

The lesson is that success or failure can be a state of mind. If you're willing to use patience and keep trying new approaches, you can always be in the process of turning failure into success where it counts—fourth dimensionally.

### **ABOUT THE AUTHOR**

Dan Coulter is the writer/producer of the DVD, "Manners for the Real World-Basic Social Skills," and other videos that can be helpful to people with Asperger Syndrome and autism. You can find more articles on his website: [www.coultervideo.com](http://www.coultervideo.com)

Copyright 2008 Dan Coulter Used By Permission All Rights Reserved



## Pat's Corner

Pat can be reached at (203) 265-7717 x14

It seems like the school year just flew by and here we are - SUMMER!

During the year the ASRC ran a weight lifting program, and all the participants really seemed to enjoy it. This is strictly a "guy" thing, run by our very own Anthony (just recently engaged to be married) and Will. It was held at the Wallingford YMCA. The staff of the YMCA have been very accommodating to our kids. Our next event for pre and young teens, girls and boys, will be on August 2<sup>nd</sup> at Community Lake in Wallingford from 9 AM until 11 AM. We will be playing volleyball, tennis and basketball. No formal games, just some "hanging out." On August 2<sup>nd</sup> we can use the barbecue pavilion, and our final meeting is on August 9<sup>th</sup>. Please let me know if you would like to join the group.

Our Golf program is yet again up and running. Our group meets on Wednesdays at 5 PM at Minor Hills Family Golf in Cromwell, facilitated by Anthony. Every season we seem to add more participants to this group and it has turned out to be very popular! The age group is 13 to 17. However, we also have a young adult group, also facilitated by Anthony. They make their own golf dates, so if interested, let me know and I will put you in touch with Anthony.

Our Respite Program, a program long overdue, meets approximately two Saturdays a month at our center in Wallingford. Typically our respite program runs from 4 until 6 PM. Staff from the Yale Child Study Center run this group and we only accept 4 or 5 children, so pre-registration is **REQUIRED**.

ASRC purchased special tickets for a Met's game at Shea Stadium for Autism Awareness Day, which was held on Saturday, May 10<sup>th</sup>. Fifty-five of our members went to the game, and what made it especially enjoyable was the fact that the Mets won!

The girl's track team from the University of New Haven participated in our 10K Run for Autism, which took place the same day as the Walk, at the

Farmington Canal Trail in Hamden. We had 144 participants, ages ranged from 13 to 82. This is not a typo; Mr. Bernstein is 82 years old and an inspiration to us all. One of our members, Amy, also participated and made a fine showing. I'm hoping to expand the number of runners next year. It was great fun! Thank you to all who participated!!

The nursing class from Lyman Hall High School in Wallingford held a bake sale and made a donation to our Walk. The nursing class from East Haven High School had a little contest going to see who could collect the most money and also made a generous donation to our Walk For Autism. It's great to see the teens interested – there are a lot of great kids out there.

Our members are most important to us, and in this regard we have offered our services to visit your child's school and talk to the children about autism awareness. I have been doing this all along with High Schools, but have now started to speak to 6<sup>th</sup> graders. I find the kids very enthusiastic and they ask a lot of questions, which is what I am striving for. If you would like to take advantage of this complimentary service, all you have to do is get approval from your school and forward the contact information to me.

Through our database we are able to link up parents with children of similar age. They have been communicating with each other and are planning some social events for their kids. If you would like to join a group or start one of your own, please get in touch with me so I can assist you.

Ladies, put Saturday, October 25<sup>th</sup> on your calendar for the Ladies Day Luncheon and Fashion Show. I will be sending out more information on this as we get closer to the event.

*Over the past several months the ASRC has been fortunate enough to be the recipient of several fundraisers around the state. We would like to especially acknowledge the following organizations for their contributions to the ASRC.*

***Thrivent Financial for Lutherans***

The CT Autism Spectrum Resource Center participated in a fundraiser in April in Stamford, CT. Sharon Alberson wrote a musical, The Peace Table, and the performance was a benefit for the ASRC, Special Olympics CT Southwest Region and PLAN of CT. Thank you to Alice Reitz, PLAN Advisory Board Member, who was actively involved in the production.

***Tolland Middle School & Bear Path School***

The ASRC would like to thank the staff at Tolland Middle School and Hamden's own Bear Path School for their generous contributions. Staff members participated in a "Dress Down Day" in which they made a donation in exchange for dressing down. During the months of April and May the proceeds raised were donated to the CT Autism Spectrum Resource Center. THANK YOU for thinking of our center!

***The Braeburn School***

The Braeburn School located in West Hartford collected supplies for our center during their "Art For Autism" event. The supplies contributed to our center were used as prizes for our top three winners in our Walk of Art contest held on May 4<sup>th</sup> at the Walk For Autism. Additional supplies were used to create a "Craftastic" basket displayed and raffled off that day as well. Thank you to the staff, students and parents who made this possible!!

***METLIFE Foundation***

The ASRC would like to thank the MetLife Foundation Volunteer Project Fund for their generous donation of \$500. This fund supports nonprofit organizations with which teams and individuals of MetLife associates volunteer. The grant was in support of the volunteers who participated in our 10<sup>th</sup> Annual Walk For Autism held on May 4<sup>th</sup>.

***Reiner, Reiner & Bendett Attorneys At Law***

In support of our 2<sup>nd</sup> Annual Run For Autism, the staff at Reiner, Reiner & Bendett located in Farmington, CT held a dress down day at their firm. Together the staff raised \$333 for our event. A special thank you to Lisa Vogler for informing her mom, an employee of Reiner, Reiner & Bendett, about our event!

***Nichols School***

Nichols School in Stratford, CT held a talent show in the spring. All proceeds raised during their performance were donated to the ASRC. Thank you to all the talent show participants, parents of the students and talent show committee for all your hard work and dedication. The staff of the ASRC thoroughly enjoyed their evening out with the Nichols School students. Keep up the good work!

**Thank You**

their sibling than to them, and may be resentful of the time and resources that are spent on their

# Meeting the Needs of Non-Affected Siblings

By Julie M. Wolf, Ph.D., License Psychologist

*Editor's note: The opinions expressed herein are those of the author exclusively*

It was Super Bowl Sunday, just a few hours before the big game, when my phone rang. It was my brother: "There is a Super Bowl party for the adult support group tonight at the ASRC in Wallingford. They said we can bring a guest, and since you sort of live near there, I thought you might want to come." I was touched. When my brother calls me, it is almost always because he needs advice about something. It is extremely rare that he would call for any other purpose, let alone to extend a social invitation to me. Unfortunately, I had a lengthy "to-do" list that evening, which I had planned to tackle with the game on in the background – much of which needed to get done by the next morning. If only my brother had given me more than a few hours notice, I could have planned accordingly. So I declined his invitation, thanking him profusely for thinking of me. I hung up the phone, and was immediately hit with a surge of guilt. Was I a terrible sister for turning down the one social invitation from my brother that I was likely to get all year? I stood there with my hand on the receiver, wondering if I should call him back immediately and accept his invitation after all. And I felt frustrated – why couldn't he have told me about this yesterday?? And touched - how sweet of him to invite me (even if the reason was my proximity to Wallingford).

This complex mix of emotions was not unfamiliar to me. It is a regular component of the experience of having a sibling on the autism spectrum. Siblings may feel jealous of their sibling with ASD and the attention they receive. They may feel that their parents attend more to

sibling. They may feel they are unfairly held to a higher standard than their sibling. Meanwhile, they may feel guilty and ashamed for having these kinds of feelings, recognizing that their sibling has special needs and knowing that they would never trade their own difficulties for the struggles that their sibling faces every day. Because of these feelings of shame, and because they do not want to add a burden to their parents' already full plate, they may be reluctant to share any of their feelings with their parents.

On the flip side, siblings often know the child with ASD better than anyone else does, and as a result have a great deal of empathy and compassion for their sibling. Many siblings comment that they are a more patient, compassionate, and tolerant person as a result of having a sibling with ASD. It was these feelings of empathy and compassion that led me to become a psychologist and to work with children with autism. And it was my own experience as a sibling that led me to develop an interest in sibling issues, and to run sibling support groups both at the ASRC and at the Yale Child Study Center. Clearly, non-affected siblings have their own unique set of needs, and yet so little support is available to siblings to meet those needs. The sibling relationship is typically the longest-lasting relationship in our lives, and siblings of individuals with ASD often choose to care for their sibling when their parents are no longer able to. Thus, ensuring that the needs of non-affected siblings are met is essential not only for the well-being of the non-affected child, but also has indirect benefits to the child with ASD. Below are some

suggestions for parents to meet the needs of their non-affected children.

*Acknowledge Right to Choose Role in Sib's Life.* Siblings have a right to their own life that is separate from the life of their sibling. A child should never be *expected* to care for their sibling with ASD. While it is reasonable to ask all children to contribute to the welfare of their family, parents should ensure that they are not expecting their non-affected child to act as a “third parent.” Even as an adult, the non-affected sibling should be given a choice as to the role they wish to have in their sibling's life – it should never be assumed that the sibling will become the primary caretaker for their sibling one day. Siblings may envision a very different direction for their lives. As a sibling reaches adulthood, families should begin to discuss what role the sibling envisions playing in their affected sibling's life, and parents should make plans accordingly to ensure care for their affected child should the sibling not elect to take on this responsibility.

*Ensure Sib's Safety.* Some children with ASD have aggressive behaviors, and siblings may be a target of this aggression. If this is the case, it is imperative that parents ensure the safety of all their children. Families should have a plan so that siblings know what to do if their safety is threatened. If parents feel unable to keep all of their children safe, they should seek professional guidance.

*Monitor Sib's Expectations for Self.* Siblings often set very high expectations for themselves, to achieve all that their sibling will not be able to achieve, and to make their parents proud. Parents should carefully monitor for the possibility that siblings are placing unreasonably high expectations on themselves.

*Have Expectations for All Children.* Parents should expect household responsibilities from all of their children, including their child with ASD, so that their non-affected children do not have a perception of unfairness. This benefits

the affected child, too, who will improve their self-care skills as a result!

*Expect Typical Sibling Rivalry.* Remember that all children fight with their siblings, and you should not expect any different of your non-affected sibling just because they have a sibling with special needs. Allow your child the right to be a typical sibling, even if that means fighting with their sibling with ASD from time to time. Certainly, do not condone fighting between your children, but deal with it in the same way you would if you did not have a child with ASD. Avoid “you should know better” language, as this places unfair expectations on the non-affected sibling who is simply acting just as all other siblings act.

*Give Non-Affected Siblings Their Own Time.* Siblings may need private time to themselves from time to time. Respect and allow this. Also be sure to give your non-affected sibling some quality one-on-one time with parents. This may mean finding a babysitter or someone to watch your affected child while you spend a few hours with your non-affected child. Make it a priority.

*Allow Sib to Shine.* If your non-affected child has a recital, a big championship game, is being honored with an award, etc., make sure to be there! Often parents miss these events because they need to remain home with their child with ASD, and because bringing the child with ASD would be disruptive to the event. Again, find a babysitter if needed, but be there! If you consistently miss these events, you risk sending the message to your child that you are not proud of their accomplishments, and that you value their sibling more than them.

*Recognize Developmental Phases.* Your non-affected child will likely have different attitudes toward their sibling depending upon their stage in development. For example, adolescents may be embarrassed to be seen with their sibling, and as a result may avoid spending time with them. Recognize that much of this is a developmental phase that your child will likely outgrow, and

don't allow yourself to become overly reactive. Find a way to compromise that acknowledges your child's feelings but also maintains your expectations for them. For example, if your non-affected child expresses embarrassment at their sibling's behaviors in public, but you have an expectation that your child spend some quality time with their sibling, you might say to them, "I know your brother sometimes embarrasses you in public, but it's important that you spend time together. How about we set aside Wednesday evenings for you to spend time with your brother *here at home.*" In this way you are acknowledging your child's feelings of embarrassment, while still maintaining your expectation that your children spend time together.

*Encourage Independence.* As they reach adulthood, siblings may be reluctant to move far from home, especially if they feel their parents are under stress or need their help or support. If your child has always wanted to go to college in California, but when the time comes suddenly states a desire to remain in Connecticut, explore this with them. Determine whether their sibling has anything to do with this decision, and if so, reassure them that it is okay for them to follow their own dreams.

*Promote Communication.* Talk to your children! Recognize that your non-affected child may not come to you to express all of their feelings, and may be reluctant to discuss their feelings about their sibling even if you bring up the topic. However, they will appreciate that you brought up the topic, because it will signal that you are acknowledging their experience. As your child approaches adulthood, continue the dialogue about what role they expect to play in their sibling's life.

*Provide Opportunities for Social Support.* Parents often join parent support groups and seek out contact with other parents who have children with ASD, because they could not imagine "going it alone." And yet, this is often what is expected of siblings! Talk with your

child about whether they would like to participate in a sibling support group. If one is not available, look into other forms of support (for example, there are e-mail listservs for siblings: "SibNet" for adult sibs, and "SibKids" for children. Your child can sign up at [www.siblingsupport.org](http://www.siblingsupport.org).)

For more information about the sibling support groups at the ASRC or the Yale Child Study Center, contact Dr. Julie Wolf at (203) 785-5337 or [julie.wolf@yale.edu](mailto:julie.wolf@yale.edu).

## ***About The Author***



*Julie Wolf has a great deal of both personal and professional experience working with individuals with autism spectrum disorders (ASD). She received her Ph.D. in clinical psychology from the University of CT, where she studied facial recognition in individuals with ASD under the mentorship of Dr. Deborah Fein. Currently, she is a post-doctoral associate at the Yale Child Study Center. In addition to her research pursuits, she has clinical interests in assessment and intervention for children with ASD.*

**ASRC - ASD ADULT AND OLDER TEEN SUPPORT AND SOCIAL GROUP**

**Summer 2008**

Our adult group is constantly adding new members. In addition to our adults, we've had good luck with some teenagers as young as 15. If you have a son or daughter who is a teen, encourage them to give our group a try. Our board games, DVDs and hikes appeal to all ages.

This is our third year hiking regularly at Sleeping Giant. We always choose the relatively easy, 3 mile round trip, Tower Trail. In addition to hikers from our group, we've had friends, family and a few dogs join us. The hikes are great, Spring, Summer and Fall. We have also hiked at the West Hartford Reservoir, Wadsworth Falls and Talcott Mountain.

In 2007 we started meeting regularly to watch DVDs at ASRC. We're fortunate enough to have a tremendous seven foot screen for the DVDs. We've seen everything from The Devil Wears Prada, to Beverly Hills Cop, to The Simpsons, to reruns of The Munsters, I Love Lucy, and Monty Python. We schedule DVDs on lots of Saturday evenings. Recently, we've watched The Incredibles, Blades of Glory, Vegas Vacation and Rat Race.

We've now been holding Board Games Nights at the Wallingford Recreation Center for more than two years. Michael S. is doing a great job running our Games Night. We routinely get about ten people playing games and socializing. We've got a few people starting to play bridge. We meet on the 1st and 3rd Thursday of the month.

We've also taken advantage of some unique opportunities. Last summer we went sailing and made a trip to a beach in Rhode Island. We've been to some Rock Cats games, mini golfing, bowling, and visited Lake Compounce and The Big E. We had a Halloween party with more than ten of us showing up in costume. We visited the Fantasy of Lights in New Haven. We also had a holiday party, a New Year's Eve party and a Superbowl party. In February, we visited the Peabody Museum.

We've got four different activities that we schedule quite regularly. We have support meetings on the second Friday. We have board games, hikes and DVDs. Between those four and our parties and infrequent outings, we are doing something every week and sometimes two or three things in the same week.

As busy as our group is, we still have plenty of room for anyone who'd like to join us. Just call or e-mail me and I'll start sending you notices as we schedule activities. Our group is intended for adults on the spectrum, but anyone who is a good fit with our group is welcome at many of our activities. We have teens, spouses and siblings who join us. And, we've had young children on the spectrum join us along with their parents. The best way to determine if our group is for you is to join us for an activity. The odds are, we have an activity coming up in the next few days.

Dave Tipping  
203 484-2937  
[NZ1J@JUNO.COM](mailto:NZ1J@JUNO.COM)

# An Update On The Work At The Center

Lois Rosenwald

Executive Director

Thanks to your continued support and participation, ASRC continues to grow. Our 10<sup>th</sup> Annual Walk for Autism was our most successful yet!

We are bringing on two new staff members in the fall to help with our growth. We are very happy to welcome Sara Locke, a parent and special education teacher. Sara has worked with us very, very part time in the past, but will be taking on more of a schedule in the fall. She will be doing some advocacy with parents, training for school personnel including paras', community provider training and she will continue to do training around safety issues for folks with ASD. She will be presenting to first responders, i.e. police, fire, medical community, schools, etc. to help all of these groups understand the spectrum better, and be more prepared to deal with our folks in emergencies and difficult situations. ASRC is dedicated to this mission and will continue to offer this kind of training as long as there is a need. Sara will also be doing training for any community group needing to understand the spectrum better. She will individualize the training for that particular group's needs. She is an extremely knowledgeable presenter and we are thrilled to have her. Our second new staff member is Carol Barans. Carol is also a parent of an ASD teenager and has been a member of our center for a long time. She is also a newly retired school administrator, with years of experience dealing with children on the spectrum as well as her own child. Again, we feel very fortunate to have Carol working with us. She will be consulting to schools and families on how to develop appropriate Transition Plans for ASD teens so that they experience more successful transitions to adulthood; this is an area that has been overlooked way too long. We know that if a child is going to be successful in life, it is vital that transition planning offer them the appropriate experiences, and those experiences need to be individualized. We hope that we will be able to be of assistance to schools and parents. Given this overwhelming need, we will be doing our first Transition Conference: it will be held on Saturday, November 15, 2008. If you are a parent of a 10 to 21 year old or in their twenties, you need to mark your calendars now! We have a very exciting and informative day planned for you. It will be held at Central CT State University in New Britain and will start at 8:30am and go thru until 4pm. Our Keynote Speaker will be Stephen Shore. It will be a day packed with information and resources. You will be receiving a flyer in August. If you have a ten year old and are thinking "I don't need to know this stuff yet", you're wrong. We have found the earlier parents get the information the better prepared they are to make the hard decisions regarding their child's future. In working with adults on the spectrum, I find the ones that are doing the best were fortunate enough to get the appropriate transition supports as teenagers.

If you feel either one of our new consultants can be a help to you, or your district, please call me for further information. We plan 2008-2009 to be ASRC's best year yet! I hope you will join us for some of our trainings and take part in some of our services.

Best,

*Lois Rosenwald*

# \* \* \* \* ANNOUNCEMENTS \* \* \* \*

## Saturday for Kids Program

Saturday for Kids is a recreation and respite program for families with children who have special needs. The program is located in Cromwell and meets 2 or 3 Saturday mornings per month, year-round. Parents or caregivers drop off their children at 9:00 AM and pick them up at 1:00 PM. Live entertainers perform once a month on "buddy days," when program members may invite a friend or sibling to attend. Toys, arts and crafts, and other activities such as bike riding and basketball are available. Kids' birthdays are also celebrated at snack time.

### Contact Information:

MARC: Community Resource, Ltd.  
Saturday for Kids Program  
421 Main Street  
PO Box #100  
Cromwell, CT 06416  
860-635-5151 x305  
[www.marcweb.org](http://www.marcweb.org)

## Calling All Volunteers

We are looking for *volunteers* for the ASRC Golf Tournament being held on October 6th. If you are available to fill a 2-hour slot, please contact Jeanine DeLucia at 203-265-7717.



## Autism Family Cruises

Royal Caribbean offers cruises geared towards families dealing with autism. All activities are structured to match each individual's abilities &

**ASD Book Donations are being accepted by ASRC**  
We are currently in the process of expanding our Members Only library and are asking for your help. If you have any related books you would like to donate, please call the center at (203) 265-7717.

## Wanted

Interested parents & teachers and others that ASRC can train to do presentations to first responders around the issues of Autism Spectrum Disorders. Our purpose in doing these workshops is awareness and providing police, Fire, EMT and personnel within the Criminal Justice System the information they need to work successfully and interact with the ASD population. We are looking for trainers that are able to do one or more workshops a month. If interested, please call Lois at 203-265-7717!

## CALL IN YOUR NOMINATIONS

We will be giving a special award to an outstanding high school teacher, social worker, counselor, psychologist or speech and language therapist at our November 15<sup>th</sup> Transition Conference. If you know of someone you would like to nominate, please call us at 203-265-7717 or mail in your nomination. Deadline for nominations is Sept. 17<sup>th</sup>.

## B.Y.O.B

The ANNEX Y.M.A. Club is sponsoring a fundraiser for the ASRC on Saturday, September 27<sup>th</sup> from 8-12pm.

**LIVE MUSIC  
COFFEE – DESSERT  
RAFFLE**

**Donation \$15**  
Tickets Available In The Lounge  
OR

Freed, Nancy Blakely, Phillip Alverson-Parris,  
Rudy Redstock



\*\*\*\*\*

## DONATIONS TO ASRC

\*\*\*\*\*



*The ASRC staff would like to thank the following people for their generous donations to our Center.*

*In Memory of Timothy Dioses*

Carey & Matthew Krebs, Ronald & Myriam  
Sargent, Nelson & Mary LaFogg, Renee Maglietti,  
Thomas & Candace Ward-McKinlay, Lucille  
Bannon, Kenneth & Karen Roth, June Cameron,  
Regina Gardner, Sharon Hurd, Diane Dellamonica,  
Lore Tomlin, Vance Friends, Bobbi Geisser &  
Family, Lois Babey-Finn, The Holmes School,  
Larry Erwich, DMD, Alicia Powers, Jorge  
Acevedo, Louise & Richard Hetrick, Cheshire High  
School Girls Swim Team

*In Memory of Bob Quarello*

Leonard & Paul Bisaccia

*In Honor of Patricia Muhl*

Madeline Dart

*Aetna Giving Campaign*

Cynthia Brandon

*Behalf of the Lyla Family*

Marjorie Abramski

*Bristol Myers – thru the United Way*

Sean Egan, Maria Pearce, John Williams, Harley  
Ferguson, Nannette Schulthess

*Car Donations*

Mark Perkins, Michael Macvittie, William  
Samela, Anne Johnson, Alexander Herrera, Curt  
Molnar, Douglas Sharafanowich, Kenneth  
Walz, Lana Tadlock, Lynn Norquist, Anas  
Ouali, August Benigini, David Nelson, Ellen  
Apicerno, Jon Blauw, Mario Barragan, Michael

*Pitney Bowes Employee Involvement Fund*  
Anonymous

*CIGNA Corporation thru the United Way*  
Anonymous

*KPMG thru the United Way*  
Anonymous

*Northeast Utilities thru the United Way*  
Margaret Shugrue, Walter Szymanski

*TD Commerce Bank thru the United Way*  
Anonymous

*Travelers thru the United Way*  
Anonymous

*General Donation to the ASRC*  
Trinity Ladies Club

*Donations thru Bristol-Myers Squibb Company*  
Ramesh Padmanabha, Marie-Laure Papi, Harley  
Ferguson, Deborah Maybach

# **DO NOT MISS OUT**

## **ASRC Transition Conference**

Mark November 15<sup>th</sup> down as a "can't miss" important conference date! ASRC will be holding a TRANSITION CONFERENCE for all parents and professionals living or working with children ages 12 through young adulthood. Our all day conference will be held at Central CT State University and limited space is available. Look for the flyer in your mail come August.

### **OUR PRESENTERS**

James Loomis, Ph.D

Jane Theirfield-Brown, Ph.D

Lori Wolf, Ph.D

Lori DeGalbo, Ph.D

Lois Rosenwald

Carol Barans

### **Keynote Speaker - Stephen Shore**

Nonverbal until four and diagnosed with "atypical development with strong autistic tendencies," Stephen Shore was regarded as "too sick" to be treated on an outpatient basis and recommended for institutionalization. His parents persistence and the help of teachers and other friends and professionals has allowed Stephen to gain more ground than anyone would have thought possible from that original diagnosis! He is now completing his doctoral degree in special education at Boston University with a focus on helping people on the autism spectrum develop their capacities to the fullest extent possible. In addition to working with children and advocating for a better quality of life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure. In his book *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, he shares his love of music and learning as he walks us through the heartaches and triumphs of his life as an Aspie. He also serves on the board of the Autism Society of America, as board president of the Asperger's Association of New England, and is on the Board of Directors for Unlocking Autism, the Autism Services Association of Massachusetts.

---

## CT Autism Spectrum Resource Center, Inc.

---

ASRC is proud to maintain a Board of Directors comprised of family members, as well as a Professional Advisory Board of respected members in a variety of fields associated with autism spectrum disorders. They are:

### Our Executive Director:

Lois Rosenwald

### Our Executive Board:

Julie Hipp, *President*  
Michael DePalma, *Co-Vice President*  
Robyn Trowbridge, *Co-Vice President*  
Dean Young, *Treasurer*  
Tina Rembish, *Secretary*  
Cathy Adamczyk, *Parent*  
Peggy Day, *Parent*  
Jadine Finch, *Parent*  
John Gawlak, *Wallingford Park & Rec*  
Christopher Lyle, *Parent*  
Tina Rembish, *Parent*  
Amy Sorensen, *Parent*  
Michael Lynch, *Parent*  
John Tangney, *Parent*

### Our Board Of Advisors:

**Karyn Bailey**  
*Yale Child Study Center*  
**Karin Bertero**  
*Dir. High Road Student Learning Ctr*  
**Jane Cannon**  
*Educational Consultant*  
**Maggie Casciato**  
*Pres. Atypical PDD/Asperger's Support Group, Inc.*  
**Ruth Eren**, Ed.D  
*Profesor, SCSU, Educational Consultant Eden*  
**Tara Glennon**, Ed.D OTR/L, BCP, FAOTA  
*Dir. Center for Pediatric Therapy*  
**Linda Grimm**  
*Dir. Benhaven Learning Network*  
**Lynne Guilmette**  
*Behavioral Development & Educational Services*  
**Marijke Kehrhahn**  
*Profesor UCONN*  
**Robin Kencel**  
*Parent & Author*  
**Larry Wood**  
*Exec. Dir. Benhaven*

**Ami Klin**, PhD  
*Yale Child Study Ctr*  
**Diana LaRocco**, Ed.D  
*Univ. of Hartford*  
**James Loomis**, PhD  
*Ctr for Children with Special Needs*  
**Wendy Marans**, MS,CCC/SLP  
*Private Practice/Yale Child Study Ctr*  
**Althea Marshall**, MA, MS,CCC-SLP  
*SCSU*  
**Michael Powers**, PhD  
*Ctr for Children with Special Needs*  
**Kathy Radziunas**  
*Wallingford Park & Rec*  
**Sara Reed**  
*President, ASCONN*  
**Nancy Schwartz**, PhD, CCC/SLP  
*Communication Clinic of CT*  
**Elizabeth Valeriay**  
*Spec. Ed. Teacher*

---

### **Our Mission Statement**

The mission of the ASRC is to provide, through our many programs, the most recent information and research to help parents and professionals understand the barriers and challenges people with ASD face on a daily basis. Our Center is committed to raising public awareness about autism spectrum disorders and devoted to empowering families and lessening their isolation. We are also dedicated to educating families, professional and the general public to the many strengths that people with ASD have and to promote the respect that they deserve.

ASRC  
101 North Plains Industrial Road  
Harvest Park, 1A  
Wallingford, CT 06492  
Phone 203-265-7717 Fax 203-265-7768