

The Sun

Newsletter

July–September 2013

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Our mission

Autism Delaware™ works to create better lives for people with autism and their families in Delaware.



The benefits of a good relationship

We all need good relationships in life. They are the foundations of a fully functioning community. For individuals and families living with autism spectrum disorders (or ASDs, for short), good relationships enable us to work well together. In turn, we can take on overwhelming challenges—and overcome them!

As a nonprofit agency that works to create better lives for people with ASDs, Autism Delaware relies on relationships with people and organizations to meet wide-ranging needs. These relationships allow us to offer recreational outings, family support, social events, advocacy at both the state and local levels, information and referrals, adult services, and clinical services.

In this article, we discuss the benefits that are possible through good relationships—with schools, families, and community partners.

One of the most significant connections any family living with autism can make is with the child’s IEP team at school. As the group responsible for the child’s individualized education program, the IEP team thrives when a positive working relationship exists between all the members, including the child’s parents or guardians.

The principal of the Sussex Consortium, Vivian J. Bush, PhD, has 24 years’ experience in the field of psychology and has heard a lot of advice being given to parents. The most important piece is that parents need to be frank with the IEP team.

“What I’ve seen most often,” explains Bush, “is that, by the time parents ask for help, they have established years of negative behavior patterns that take harder work to fix than if the behavior had been addressed when the child was younger. Sometimes, parents do

not even realize the measures they go through every day just to keep the peace at home. Then, one day, they are facing a child who is presenting a danger to him- or herself or using his or her strength against the family. Choices become limited. ‘How did we get here?’ they wonder. ‘And how do we fix it?’

“Families with children with autism have a host of confounding emotions, such as grief, guilt, and anger, all mixed in with love,” continues Bush, “so the hardest thing these families ever do is open their doors to strangers and expose their insecurities and weaknesses. These families may think their lives are not perfect. But whose life is? Accepting life as it is and being completely honest about it may be the only way for anyone to help them—even if they are offered solutions they may find difficult to accept.

“As school professionals,” adds Bush,

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Sean Tuohy at Walk

The Sun

A publication of Autism Delaware™

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A time of transition and gratitude

A time of transition is typically stressful. For children and adults with autism—when transitioning from one activity to another, from one school to another, and from school to adult life—the anxiety is even greater.

As a community living with autism, we don't like to deal with transitions, but Autism Delaware has been going through an extreme transition this year. Did you notice? We are pretty sure you didn't, thanks in large part to the foresight of our recently retired executive director, Theda Ellis, and her successor, Teresa Avery.

Theda was Autism Delaware's first executive director. We hired her in 2002, when we were still an all-volunteer group working mainly out of my home in Wilmington. Little did Theda realize as she headed to my home for the job interview that she would end up working there, too, for nearly two years. Her ability to take that little job issue in stride—as well as to work through breast cancer treatments during her first year on the job—both are testaments to Theda's indomitable spirit and passion and dedication to the autism community.

Theda changed everything when she came on board. In her 10 years as our leader, she connected us to statewide systems, organized us into a profes-

sional nonprofit, and grew Autism Delaware into the force that it is today. Her ability to envision "the big picture" while seeing to day-to-day details was invaluable. It wasn't always easy. There were plenty of bumps in the road, but Theda never wavered from her belief in what we were doing or in her commitment to moving forward.

Theda also set the stage for a smooth transition into her retirement. During her last two years as executive director, she implemented a gradual handoff of responsibilities while grooming her successor. This strategy allowed Autism Delaware to move seamlessly into a new era—a rare feat for any business much less a nonprofit. No words can describe how grateful I am, as a parent and as the Autism Delaware board president, for all that Theda has done.

That said, I want to officially welcome Teresa Avery as our new executive director. Teresa is already well known to many because she served as Autism Delaware's associate director before succeeding Theda. If you have met Teresa, you know that she brings a tremendous energy and positive attitude to our community. When Teresa comes into the room, the whole spirit of the room lifts. What a gift for those of us struggling with autism and its many challenges.

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Marcy Kempner
President
Autism Delaware



Theda and Warren Ellis at the Auction for Autism

A service of Autism Delaware



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A time of transition and gratitude
Continued from page 2

Teresa also brings valuable business experience, terrific organizational and management skills, and a work ethic that causes me to tell her from time to time “Take a day off!” Come to think of it, that used to be a “problem” with Theda, too. We are truly fortunate at Autism Delaware to have had Theda Ellis as our first executive director and now to have Teresa Avery leading us into the future.

So the next time you experience the stress of a transition, remember that Autism Delaware offers many supports and services to help you through, including parent-to-parent connections, autism friendly family activities, behavioral therapy services, and our nationally recognized adult services program, POW&R.

Or just come by the office, and visit with Teresa to see that a transition can be a truly positive experience!

Marcy Kempner



Slam dunk for Autism Delaware

Standing outside the Autism Delaware Milton office, the staff shows off a big check from Saint Mary Magdalen School. The Wilmington, Del., high school raised \$11,300 during its eighth annual 3-on-3 basketball tournament, a two-day competition intended to benefit Autism Delaware. Including students from other Catholic high schools in the area, 127 teams played 236 games over the two-day March event.

“The highlight of the event,” notes Barbara Wanner, principal of St. Mary Magdalen School, “was the presentation of a check representing the intended donation to Autism Delaware. In the end, St. Mary Magdalen School raised \$11,300 to help people and families affected by autism in Delaware.”

“This donation is one of the largest we have ever received from a third-party event like the St. Mary Magdalen School basketball tournament,” says Autism Delaware Executive Director Teresa Avery. “We are very grateful for the donation and can guarantee that—with one in 88 children now being diagnosed with autism spectrum disorders—the funds will be put to good use.”

What are Delaware’s PTAs doing?

Representative of the Brandywine Specialized Autism Program parent teacher association, **Beth Murphy**—

“Twice in the last year, Vince Winterling, EdD, [director of the Delaware Autism Program] was a guest speaker. He discussed toilet training and behavior management.

“The PTA has also prepared for this fall when, for the first time, 9th- to 12th-grade students on the spectrum will attend Mt. Pleasant High School. They had been attending Newark High School because the program went only to the 8th grade.”

Tax-free savings with no risk to benefits

The Achieving a Better Life Experience Act (S. 313/H.R.647) is back in the U.S. Congress. Known as the ABLÉ Act, it lets people with disabilities and their families create tax-free savings accounts for future use—with no risk to eligibility for benefits. The ABLÉ Act would let people have the dignity of saving, financial management, and personal investment in their progress through life without removing the supports that they will need on a regular basis. In some cases, these savings could help them rely a little less on public programs.

An ABLÉ plan will function much in the way that a 529 plan does for future college costs but for the unique future needs of people with disabilities. Qualified expenses include education, housing, transportation, medical and dental care, assistive technologies, employment training, and community supports. For

example, a man with Asperger’s syndrome could save to buy a reliable car to get to work without losing the publicly funded job coach who helps him maintain his position. A teenager with autism could save for a post-secondary life skills program and still be eligible for support services when she completes the program. And parents could put aside money for their children’s dental care that is not currently covered by Medicaid for adults.

The bill has strong support across the disabilities community, and U.S. Sen. Chris Coons and Rep. John Carney have signed on as cosponsors.

As updates on the ABLÉ Act happen, we will post them through Autism Delaware’s listserve (Googlegroup: Delaware Autism) as well as on our website under Advocacy>Issues & Positions.

PARENT PARENT

Building a relationship that can aid transition

Transitioning your child to a new school is like peeling an onion: Each layer has a bit of a learning curve, and just as you remove one layer, one more is right behind it.

Each stage of your child's school experience will bring added learning curves and adjustments, but the basics don't change. These basics start with getting to know the team supporting your child's individualized education program (IEP). This IEP team includes the teacher and paraprofessional as well as a possible speech or language pathologist, physical therapist, occupational therapist, adapted physical education teacher, music therapist, administration, and the school nurse. Your child's needs determine who the team members will be.

As the parent, you have a place on the team, too. Your job is to explain your child's personality and learning style to the IEP team and communicate your concerns as well as the challenges and goals that you want your child to accomplish. Remember: The IEP can be changed when you see the need to change it.

Read about your rights in an IEP meeting. Start with this U.S. Department of Education website: <http://www2.ed.gov/parents/needs/speced/iepguide/index.html>.

Also, learn about the IEP document itself. The IEP can seem daunting because of the ton of paperwork involved—but don't panic. Instead, talk to other parents and the teacher about the process of assembling an IEP. Or take a seminar. The Parent Information Center (PIC) of Delaware offers seminars. Learn more at picofdel.org.

In addition to getting to know the IEP team, get to know

the school. Moving from elementary school to middle school, for example, brings about changes to routine, such as waking time and navigating the school building if it's in an off-site location. And don't forget the usual bus driver and teacher changes. To learn about each school and its teachers, network with the parents of children who have been through the transition ahead of your child. The more you know going in, the better experience you and your child will have.

Also, each time your child is assigned a new teacher, help the teacher get to know your child. Consider writing a short biography about your child: What does he like to do at home? Does he have any pets? What about siblings? Include their names and ages. And remember to include the things that make your child unique. If the teacher knows that your child hates carrots but will eat peas, the teacher can help make lunch time easier for your child.

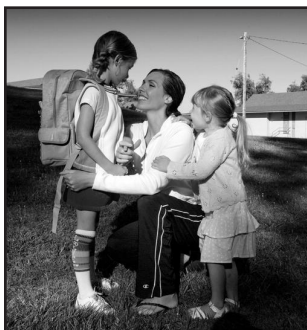
Daily communication is vital, too, because what happens at home can carry over into your child's school day. For example, if the bus is late and, as a result, your child is anxious and upset, the teacher needs to know what to expect when the bus arrives at school. So, email the teacher or leave a voice message at school. Communication is key, so share important information about your child with everyone who needs it.

—Jen Nardo



Jen Nardo's son, Jake

Four tips for reducing back-to-school stress



The president of the New York Association of School Psychologists, Peter Faustino, PhD, lists four tips in his article entitled *Back to school for children with autism: Tips for reducing the stress associated with back to school*.

Tip #1: Say hello to the school again

Make time to meet and greet the key people in your child's school for the upcoming year. Regular communication with the school is essential, so be sure to say hello again. Start by seeing if a school professional can help you with just the little things at first: a visit to the school before it opens, practicing the combination of the locker, a schedule of the times that things will happen at

school, or some guidance on the key things to be learned in that year. It is best to start with small requests before you ask for the big favors as the year progresses (things like helping with the school bus, setting up some peer buddies, or managing a bully). Once you find a school professional that is a good listener, then you can begin to explain the nuances of your child. Help [him or her] understand who your son or daughter is beyond what can be gleaned from an IEP [individualized education program].

Tip #2: Begin the adjustment

Try to adjust your child's environment to resemble the back-to-school schedule. Start by highlighting a calendar to show your child when school starts. Then begin to adjust your bedtime and morning routines slowly so that they mimic the school schedule. This will help you avoid a September shock. Even if your child wakes, gets dressed and then falls asleep again—the rehearsal of the morning routine should save you

Continued at the bottom of the next page

Of all the things to manage in my daughter's world, one of the most nerve-wracking was facing Laura's transition in 2004 from the protective world of the Delaware Autism Program to "the real world." My sweet little girl was about to be without the caring and attentive safety net of the DAP!

Fortunately, we, her parents, were laser beam focused on a vision of the life we wanted for Laura. This life revolved around work in a caring and protective environment, great role models, and the community. Most of all, we wanted Laura to have fun and to engage in things she would enjoy. For us, it was about "getting a life."

With DAP helping us to manage the transition, Laura started her work career at a local hair salon and spa, where she still works after nearly nine years. And with assistance from Community Integrated Services and Comfort Keepers, we were able to round out Laura's day, including time for community activities and fun.

As parents, we have to create the life we see for our kids. Simply be vigilant in working to create its reality. Seek out the supports you need, and then work to ensure that they can be put in place for the long term. And like Laura, despite it all, try to have fun!

—Gary Pollio

A father's voice

Men talk about their hopes, dreams, and effort on behalf of their children with autism spectrum disorders

I am so proud of my son and what he has accomplished thus far in life. He has overcome some difficult challenges, such as fitting in after we moved from the Midwest and graduating from high school. My son has become an articulate and ambitious young man.

The biggest challenge we now face is my son's transition from a prolonged adolescence to manhood. Diving into the job market, deciding on a college major (or college at all), getting around with his own driver's license, and making friends are challenges that every young adult faces and that I look forward to helping him to overcome. I don't like to define him or set expectations for him just because he happens to be living with Asperger's syndrome.

In many ways, being the father of an Aspy is really no different than being the father of any other child. I have found sources of patience that I never knew I possessed as well as multiple ways to explain things multiple times so that my son understands and remembers. I have embraced the philosophy of "sometimes embarrassed but never ashamed," and it has served our family well.

—Bernie Janoson

Four tips Continued from the previous page

stress when the first day arrives. Also, try to plan lunch and snack time activities similar to the school schedule. If your body physically adjusts, then it will be easier to adjust emotionally as well. Think of it as jet lag for school—you will need a few days or weeks to completely acclimate, so start now.

If there is time, select some educational topics that your child might be covering this year. Whether it be the IEP goals that will be addressed or some curriculum-related topics, exposing your child to these things ahead of time can be of great benefit. Don't get frustrated or upset if your child is having difficulty at first. The learning curve is the steepest upon first exposure, so remind yourself that you are making the task easier for when your child starts school—There is no need to master the activity in August.

Tip #3: The schoolyard hook

All developmental age ranges and genders have what I call a "social skills hook." This is something or several things that other boys and girls are interested in that your child can use as a connection to others. Opportunities are everywhere, but we need to maximize these windows of social connec-

tions. While most children with ASDs have varying degrees of restricted interests, you can still find a way to meld their particular interests into something social—then, you have the hook. If possible, visit the playground or recess area... or the high school cafeteria or commons areas... to practice and rehearse the hook. If you are having a hard time finding a connection to peers, then ask one of the school professionals for some guidance. They can sometimes facilitate an interaction and then offer you some advice on the best ways to maintain these interactions throughout the school year.

Tip #4: Stay positive

Living with autism can be overwhelming: It is all too easy to think about past trials and worry about another school year. Back to school is an adjustment for everyone in the house, especially caregivers. But you can keep up hope if you stay optimistic. Find something that your child can look forward to and become excited about in September. This might help associate change with something positive. If you look for strengths, then you will see what is possible and perhaps you just might recognize something that wasn't there before: a learned skill, a different smile, or a new friendship.

INSIDE **Autism**[™] Delaware

Raising awareness of autism's impact

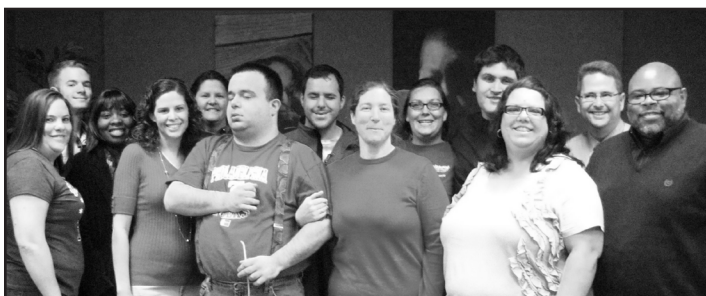
April was Autism Awareness Month, and this year, Autism Delaware raised awareness by addressing the impact of the developmental disability on Delaware's families.

"Last year," says Teresa Avery, MBA, Autism Delaware's executive director, "the Centers for Disease Control and Prevention announced that one in every 88 American children is now being diagnosed with an autism spectrum disorder. These numbers are skyrocketing. In fact, according to a CDC study released this year, the prevalence may be as high as one in 50—which means a lot more families are struggling with the myriad issues around autism. From early intervention services for our very young children to employment and social opportunities for our adult population, the need grows with the number of people who are affected by autism. We work to create better lives not only for people with autism—both across their life spans and across the state—but also for their families."

Of the numerous events planned for Autism Awareness Month, one highlight was Autism Delaware's Smart Cookie Day. Created to give families the opportunity to share their stories with their state legislators—as well as chocolate chip cookies baked by students at the Delaware Autism Program (DAP)—Smart Cookie Day includes a resolution declaring April as Autism Awareness Month plus a casual evening reception with elected officials.

"Smart Cookie Day provides our families with face time to seek change and share their unique stories with their legislators," notes Kim Siegel, MPA, Autism Delaware's policy and walk director. "Seeing the impact of disabilities on families struggling to find treatment or sacrificing their future to get their children what they need is best presented and understood in person."

Autism Delaware also supported the Autism Speaks worldwide initiative to Light It Up Blue on World Autism Awareness Day. "Thank you, Dover Downs, Woodburn, and Legislative Hall for joining the initiative," continues Kim. "Sussex County along the circle in Georgetown and numerous families also deserve thanks for lighting up their homes."



Autism Delaware's Newark staff gathered to observe World Autism Awareness Day on April 2.

Welcome, Troy Nuss!



Troy Nuss joined Autism Delaware this past winter as the new development director. Troy is charged with planning and executing a complete fundraising plan for the organization, including managing and evaluating the results of all fundraising efforts. He will also support special event directors, coordinators, and committees, working to identify possible expanded donor relationships. Before joining Autism Delaware, Troy served as the director of development for the EastSide Community Learning Center Foundation, which operates East Side Charter School, and for Highfield, the Masonic Home of Delaware, Inc.

Grants and scholarships

Autism Delaware awards community grants annually in support of organizations that provide needed services in Delaware while aligning with the autism agency's goals and mission. To be eligible for a grant, the organization must explain how the grant funds will specifically impact the autism community, submitting a detailed budget. Although the amount available for the grant will vary according to Autism Delaware's annual budget, each grant recipient can expect a maximum of \$2,000.

In addition, Autism Delaware awards scholarships in support of students pursuing higher education. The Autism Delaware Daniel and Lois Gray Memorial Scholarship is available to an eligible University of Delaware undergraduate or graduate student working toward a professional position in the autism community. And the Autism Delaware Adult with Autism Scholarship supports an adult with an autism spectrum disorder (ASD) who wants to attend college or some other post-secondary educational program.

Read about the grant and scholarship winners at autismdelaware.org>Groups & Events>Support & Education.

Did you know?

Autism Delaware™ offers financial assistance to attend autism-related conferences. For details: autismdelaware.org>Groups & Events>Support & Education>Scholarships, Groups and Stipends.

NASCAR fans take part in first annual Drive for Autism Tweet Challenge

As the field of NASCAR champions got the go-ahead to start the 2013 Drive for Autism Celebrity-Am Golf Outing on May 30, fans stayed connected through the first annual Drive for Autism Celebri-Tweet Challenge.

A sample of the participating drivers includes Jimmie Johnson, Kasey Kahne, Denny Hamlin, Kevin Harvick, Darrell and Michael Waltrip, Bobby Labonte, and Kurt Busch.

Fans of football, baseball, and TV or radio personalities received tweets from A.J. Feeley, Qadry Ismail, Kyle Eckel, Brian Billick, Vince Papale, Ben Davis, Casey Boy from *Preston and Steve* on 93.3 WMMR, sportscaster Krista Voda, FOX Sports announcer Mike Joy, and motorsports journalist Bob Dillner.

Throughout the day, these celebrities—and more—tweeted their fans while playing 18 holes of golf at the DuPont Country Club in Wilmington. Their goal was to share the day's fun while fundraising for much-needed Autism Delaware programs and services.

"Because our celebrities enjoy some time off by playing golf at the Drive for Autism, this event is closed to the public," explains the event chair, Artie Kempner, "but the celebrities still want to stay connected to their fans.



"The challenge is a fun way for fans not only to stay connected but also to help fundraise for one of their celebrities' favorite causes. And the prize is the coveted championship belt!"

causes. And the prize is the coveted championship belt!"

Volunteers are the only human beings on the face of the earth who reflect this nation's compassion, unselfish caring, patience, and just plain love for one another.

—Erma Bombeck
American humorist
(1927–1996)

INSIDE Autism™ Delaware

2013 Walk for Autism breaks records!

The largest number of walkers ever to come out for Autism Delaware's Walk for Autism event hit the trails in Lewes and Wilmington in April. Nearly 3,000 walkers helped the non-profit organization smash its fundraising goal by raising more than \$210,000. Since the Walk for Autism began in 2007, the event has raised a combined total of well over \$1,000,000 for autism services and supports in Delaware.

"The Walk for Autism is the perfect time not only to build awareness," says Autism Delaware Executive Director Teresa Avery, MBA, "but also to fundraise in support of an unprecedented number of families now affected by autism spectrum disorders in Delaware. By surpassing our 2013 fundraising goal, we raised one million dollars since the Walk for Autism first stepped off seven years ago. Given the skyrocketing numbers and need, we are very grateful for this generosity."

Thank you, volunteers, donors, and sponsors!

Volunteers, donors, and sponsors ensured that more of the funds raised by walk participants actually goes to Autism Delaware programs and services. The \$210,000 raised this year will support the growing number of people and families affected by autism throughout the state.

Sponsors included The News Journal/delawareonline, Kiss 95.9, Q105, 1410 WDOV, 94.7 WDSD, Froggy 99.9, 92.9 TOM-FM, Casale Construction, WDEL 1150AM, 93.7 WSTW, AdvoServe, Bath Fitter, Bear-Glasgow Dental, Cape-Gazette, Carman Fiat, Jolly Trolley, Peninsula Dental, Giant, Highmark BCBS Delaware, Corporation Service Company, Lorne & Sharon Solway, and Tybout, Redfearn & Pell. Other sponsors included the Beebe Medical Center, Brain Balance Achievement Center, Burns & McBride, Chesapeake Cares/Sharp Energy, Del-One Foundation, John F. Kleinstuber & Associates, Next Generation DJs, Pyramid Educational Consultants, and Service Source.



Andrew Zeltt



Ken Arni



Andrew Zeltt



Ken Arni



Andrew Zeltt

Autism Delaware Junior Golf Program

Led by golf pro and coach Butch Holtzclaw, the junior golf program is designed for youth with ASDs aged 8 to 21. Each child attends one 30-minute session per week that is geared to the child's level of ability and interest. *Registration forms are required.*



Place: The Rookery Golf Course in Milton

Weeks: August 26 & 29
September 9 & 12
September 16 & 19
September 23 & 26
September 30 & October 3
October 7 & 10

Register: (302) 644-3410
dafne.carnright@delautism.org

Autism Delaware Summer Day Camp

Designed for children with ASDs who will be enrolled in grades 3–11 for the 2013–14 school year, summer day camp emphasizes communication, social skills, and self-esteem by working on personal skills while having fun. Activities include sailing, kayaking, swimming, a low ropes course, and arts and crafts. *Call to see if slots are available.*



Place: Children's Beach House in Lewes

Dates: August 19–23

Register: (302) 644-3410
dafne.carnright@delautism.org



CALENDAR of EVENTS

July

- 3, 10, 17, 24, 31**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Heidi Mizell at heidi.mizell@delautism.org. Or call (302) 224-6020. Ext. 205.
- 9**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.
- 12**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 13**—Sensory friendly movie: *Despicable Me 2*. Minimum seating: 25. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. *Register:* Liz Carlisle at (302) 644-3410.

August

- 7, 14, 21, 28**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Heidi Mizell at heidi.mizell@delautism.org. Or call (302) 224-6020. Ext. 205.
- 9**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 13**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.
- 18**—Autism Delaware Beach Picnic. Cape Henlopen State Park. 15099 Cape Henlopen. Lewes. 11:00 AM–4:00 PM. *Register by August 5:* Email liz.carlisle@delautism.org or call (302) 644-3410.

September

- 4, 11, 18, 25**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 10**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.
- 13**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 21**—Blue Jean Ball. Rehoboth Beach Convention Center. 229 Rehoboth Av. Rehoboth Beach. 6:00 PM. *Tickets:* autismdelaware.org.
- 28**—Sensory friendly movie: *Cloudy with a Chance of Meatballs 2*. Minimum seating: 25. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. *Register:* Liz Carlisle at (302) 644-3410.

Updated resource guide

Send your email address to delautism@delautism.org, and we'll send you an updated resource guide.

Parent Coffee Hour

Panera Bread

3650 Kirkwood Hwy.
Wilmington
July 9 @ 7:00 PM
August 13 @ 9:00 AM
September 10 @ 7:00 PM

Join us!

Georgia House Restaurant

18 S. Walnut St., Milford
September 19 @ 9:00 AM

Surf Bagel

17382 Coastal Hwy.
Lewes
July 17 @ 9:00 AM

Holiday Inn Express

1780 N. Dupont Hwy.
(Behind McDonald's)
Dover
August 13 @ 9:00 AM



Autism Delaware Beach Picnic

Cape Henlopen State Park

Sunday, August 18 11:00 AM–4:00 PM



Autism Delaware brings the burgers and hotdogs; you bring the side dishes and drinks for your family.

To register:
Send an email by August 5 to liz.carlisle@delautism.org.

2013 Blue Jean Ball

Support families living with autism, and enjoy the southern Delaware event of the year!

Date: **September 21**

Time: **6:00 PM**

Place: **Rehoboth Beach Convention Center**

Tickets: autismdelaware.org



Be a superhero for autism!



2013 Auction for Autism

Saturday, November 16

6:00 PM

World Cafe Live at The Queen
500 North Market St., Wilmington

Reserve your tickets at autismdelaware.org.

Teen/Tween game night

For 9–19 year olds with Asperger's syndrome

Place: Autism Delaware™ Newark office

Dates: July 12
August 9
September 13

Time: 6:30–8:30 PM

Cost: **\$30 per season** (includes three sessions)
Must be paid at registration

To register: (302) 224-6020
delautism@delautism.org

For 9–14 year olds with Asperger's syndrome

Place: Autism Delaware™ Milton office

Dates: July TBD
August TBD
September TBD

Time: 6:00–7:45 PM

Cost: **\$10 per session**
Must be paid at registration

To register: (302) 644-3410
dafne.carrnight@delautism.org

Summer 2013 season

The benefits of a good relationship Continued from page 1

“we know that autism is a 24-hour-a-day, 7-day-a-week job and that schools touch only a small portion. The rest falls on the family. With an empathetic ear, the IEP team can offer support and help. Being honest with the IEP team is hard, but it can be the most critical tool for moving toward a successful outcome.”

Experts agree that preparing for each IEP meeting is key. Begin by answering these questions concerning the child or sibling with an ASD:

- What do you want?
- What does the school want?
- What action do you want the school to take?
- How motivated is the school to give you what you want?
- What prevents the school from giving you what you want?
- How can you address the school’s concerns and fears?

Note, too, that the questions change focus when the child is about 14. At this time, the issue becomes the transition to adult life. Your goal is to make sure that all the child’s needs for education and training are met before aging out of the school system at 21.

“This information is covered in depth in *Wrightslaw: All About IEPs*,” notes Autism Delaware Resource Coordinator Heidi Mizell, “and every parent who has a child with autism should have a copy.” Written by Peter W.D. Wright, Esq., Pamela D. Wright, MA, MSW, and Sandra W. O’Connor, MEd, this book contains concise answers to frequently asked questions about IEPs.

“To prepare a child with an ASD to meet a life goal,” continues Heidi, who is also the mother of an adult son with Asperger’s syndrome, “each child requires an education that enhances the child’s abilities, addresses the disabilities, and reaches specific goals. Autism Delaware offers support by guiding parents to an understanding of their children’s needs.



Jaclyn Dotson at work

This includes the accommodations and support they need for academic, behavioral, social, and emotional success.”

A good relationship with a child’s school can continue through the transition process and into adult life with help from Autism Delaware’s adult services program. Known as Productive Opportunities for Work & Recreation (or POW&R, for short), the program provides a range of services—community-based vocational services; competitive, supported, and self-employment; and social and recreational opportunities—to individuals with a range of needs.

“To offer all these services,” explains Autism Delaware’s POW&R director, Katina Demetriou, “we build relationships on a number of fronts, beginning with potential community partners. Each community partner is an organization do-

ing business in the community. It has its own needs, standards, and work culture. Once we fully understand these factors, we work to place the right person in the right job.”

Among the many benefits to community partners, Autism Delaware not only matches the organization’s needs with a POW&R participant’s skills but also teaches the POW&R participant to do the job the way it needs to be done. POW&R assists with operational efficiency and provides ongoing supports for quality assurance, too.

“We expect customer satisfaction,” continues Katina, “so a trained staff member accompanies each POW&R participant to work. The staff, having learned the job as well, is able to support the POW&R participant when needed. People with autism sometimes need reinforcement when learning a new process. Or depending on the individual’s disability, the new employee may need to modify the work environment for a better fit, like setting up a work area to accommodate sensory needs.

“With the right fit of individual to community partner,” adds Katina, “we can create a win-win situation.”

Since Susan L. Peterson, PhD, BCBA-D, began overseeing Autism Delaware’s new

Clinical services expanded

clinical services pilot program, the clinical director has been doing functional behavioral assessments, independent educational evaluations, and consultations with school districts as well as with families living with autism. Recently, Susan added the second version of a widely acclaimed assessment schedule plus the treatment plan known as parent-child interaction therapy (PCIT).

The assessment schedule—the autism diagnostic observation schedule (ADOS)—helps assess and diagnose ASDs across ages and developmental and language skill levels. “ADOS is a standardized way to look at how a child communicates and plays,”

explains Susan. “I can also assess restricted and repetitive behaviors.

ADOS-2 includes a toddler module that can be used with children as young as 12 months old. And for adults with ASDs, the ADOS-2 is one of the few reliable tools we have for assessment and is considered the gold standard.”

PCIT was originally developed for children, aged 2 to 5, with conduct disorders. “The growing body of evidence,” adds Susan, “shows that PCIT can also be successfully used with high-functioning children as old as 9. As many as half the children in this range are diagnosed with conditions targeted by PCIT, such as ADHD (attention deficit hyperactivity disorder). I tailor PCIT to the needs of each child and family.”

Less stress, more fun

Contributing writer Tyler Anaya is a past Autism Delaware intern who graduated in May with a master's degree in administration of human services. She also has a son with Asperger's syndrome.

Summer and holiday vacations can be nice breaks from routine for your child or sibling on the spectrum—if you plan ahead. Make these times less stressful and more fun with a few suggestions from Autism Delaware's clinical director, Susan Peterson, PhD, BCBA-D.

What can you do for a child who is used to, and relies on, daily routines?

- Use schedules already in place, but lengthen the time for fun and special activities.
- Plan to engage in different activities throughout the day, and break them up as much as possible.
- Keep your family active by alternating between physical and sedentary activities.
- Encourage flexibility, but stick with tried-and-true activities that the child enjoys.

How can you prepare a child on the spectrum for spur-of-the-moment schedule changes?

Prepare some activities that can be done at a moment's notice. For example, keep some newspapers or tissue paper on hand for tearing into strips or small pieces to make a collage. This activity will let children have fun while getting creative.

Keep a "bag o' fun" on hand. Collect small toys in a bag that you can carry while running errands or facing a long wait. Make the bag special by choosing toys the child doesn't always have access to.

What other suggestions can you offer?

Schedule "me" time for yourself. Respite providers are available; use them regularly.

Update

Autism Planning Initiative

Working towards the completion of a state plan for autism services in Delaware, a group of stakeholders has been meeting for the last 18 months. Led by Annalisa Ekbladh, a staff member at the Center for Disabilities Studies who is also the Autism Planning Initiative program coordinator, the stakeholders comprise representatives from local educational agencies (LEAs) and the Delaware Autism Program (DAP), medical professionals, Autism Delaware, Parent Information Center, various state agencies, and parents of children with autism spectrum disorders (ASDs).

The group began by evaluating the state's needs when trying to provide services to individuals with ASDs over their life spans. The group then drafted a plan for improving these services. The areas determined as needing improvement include the following:

- identification, diagnosis, and classification of autism
- training and technical assistance
- pre-professional training
- self-determination and self-advocacy
- social network development
- transition to adult life
- family support and stakeholder engagement
- systems coordination

To date, the final draft of the state plan has been completed, and the group is now working on identifying resources for putting the plan into action.

Questions

Please contact Autism Delaware at (302) 224-6020 or (302) 644-3410. Or call the Center for Disabilities Studies at (302) 831-6974.

Thank you, Dover Downs!

In a move that filled a long-time need and thrilled Autism Delaware staff and administra-

tion, Dover Downs Hotel & Casino and Dover International Speedway donated new office space to the nonprofit autism agency.

The Dover office is now one of three statewide, including offices in Newark and Milton, that will help meet the needs of the autism community in Delaware.

"We are so fortunate," says Autism Delaware Executive Director Teresa Avery, "to have the support of Dover Downs Hotel & Casino and Dover International Speedway. This wonderful office space is one more example of the many ways they are committed to supporting Delaware families."

The Autism Delaware Dover office will provide adult services, clinical services, and family support. Office hours are by appointment.

Call to make an appointment for the Dover office:

(302) 224-6020

(302) 644-3410



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Blue Jean Ball

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Auction for Autism

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**Reserve your tickets at
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