

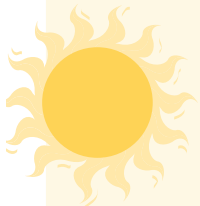
The Sun

Newsletter

July–September 2012

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Our mission

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



Your child's education



"Your job as the parent of a child with autism," begins Heidi Mizell, a parent mentor and the Autism Delaware™ resource coordinator, "is to advocate on behalf of your child. Where autism has limited your child in life, you want to create ability and possibility. And you can do this through education."

You can help create the best education possible for your child through the Individuals with Disabilities Education Act. IDEA ensures that each child with a disability in the U.S. receives the educational services he or she needs to reach a reasonable level of independence and self-sufficiency in life. In Delaware, state and public agencies provide these federally mandated services through early intervention, special education, and related services. Infants and toddlers (birth–2 years of age) with disabilities and their families receive early intervention services under IDEA, Part C. And children and youth (3–21 years of age) receive special education and related services under IDEA, Part B.

In January 2008, IDEA added language regarding students with autism spectrum disorders (ASDs). Because students with ASDs have unique educational needs, each individualized education program (IEP) must be developed around the specific student's individual-

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What do the new numbers for autism mean?

by Theda Ellis, M.B.A., M.Ed.

We were all shocked to get the new numbers from the Centers for Disease Control and Prevention: About one in every 88 eight year olds has been identified with an autism spectrum disorder (ASD). The rate for boys is one in 54.

What do these numbers mean for Delaware?

Staff spent some time reviewing public information in an attempt to estimate how many Delawareans have autism. This was not an easy process. We cannot assume that the one-in-88 prevalence crosses all ages, so we did not project numbers based on census data. Instead, we looked at public information reported by the Department of Education (DOE) and the Delaware Division of Developmental Disabilities Services (DDDS) and then developed a conservative estimate: 1,300 Delawareans have ASDs. (For more, visit www.delautism.org, and click on About Autism and Statistics & Studies.) We suspect this number is probably higher.

Why do we think our number is conservative?

The DOE and DDDS figures do not include children attending private schools or being home-schooled. The figures also exclude individuals of any age who have not registered for or used state services. The figures further exclude adults who never received services or who may be misdiagnosed. While diagnoses for children with classic autism

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The Sun

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Living in the land of denial

If you are like me, when your child was first diagnosed with autism, you went into immediate denial: "He may do this thing, but he doesn't do that thing. Look how cute he is! This can't be autism!" I clung to the hope that Ethan had only a mild speech disorder—until finally, finally realizing that the autism diagnosis was actually a relief. Having an explanation for all of Ethan's issues—and a way to start dealing with them and connecting to other families—made my life so much better.



Marcy Kempner and sons, Jack, Ethan, and Matt

So why do I keep falling back into those same patterns of denial? When Ethan turned 16 last year, his school team told me to apply for services from the Delaware Division of Developmental Disabilities Services (DDDS). I got a copy of the application, but it sat on my desk for a year. "He's not an adult yet," I told myself. "Maybe if I don't do this, he never will be."

Puberty can be scary enough, but with each of Ethan's new hormonal issues and hygiene needs, my family and I had to adjust, adopt new strategies, and accept that Ethan won't be a cute little boy forever. Denying that Ethan will become an adult will not stop it. And denying it for too long will only make life more difficult.

Pushed (again) by Ethan's school team, I finally turned in the completed application this spring. It felt good. Until I learned that adult service budgets at DDDS are planned five years in ad-

vance. So, when I finally got that application in this year, I was actually a little late. (To download the forms from the DDDS website, visit <http://www.dhss.delaware.gov/ddds/forms.html>.)

Attending the Transition Conference in April, I was reminded that many resources are available to help make the transition from school to adult life easier. (For more about the conference, see page 11 of this newsletter.)

Autism Delaware™ is here to help parents move past denial at each

stage of life and to cushion reality by offering a range of social opportunities, information, support, and advocacy. For parents of young children, we enhanced our parent packet and made the information more accessible online. We are starting to offer behavioral support services for families struggling at home. And our POW&R™ program offers really good news for those worried about the future. Thanks to the work we are doing together, there are great statewide opportunities for adults with autism in Delaware. In other words, we continue to work to create better lives for people with autism and their families. It's our mission.

I hope you connect with Autism Delaware in some way: Volunteer, write something for *The Sun*, attend a family event or parent coffee hour, or join the Google group. Just get connected with other families living with autism. Because living in the land of denial is no life at all.

Marcy Kempner

A service of Autism Delaware

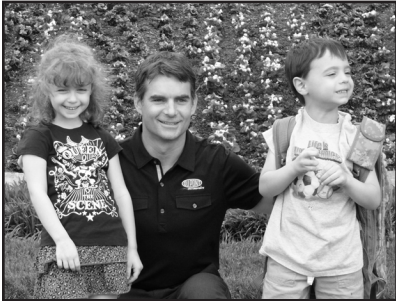


- Katina Demetriou**, POW&R Director
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Bus: 302.224.6020 Ext. 206 **Cell:** 302.824.2252
- Karen Anderson**, N. Delaware POW&R Coordinator
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- Melissa Martin**, S. Delaware POW&R Coordinator
melissa.martin@delautism.org
Bus: 302.644.3410

2012 Drive for Autism Celebrity-Am Golf Outing High percentage of raised funds goes to Delawareans living with autism

A high point in the Autism Delaware™ spring season, the 2012 Drive for Autism Celebrity-Am Golf Outing teed off on Thursday, May 31, at the DuPont Country Club.

Photo by Andrew Zeltz



Enjoying the photo op at last year's event are Marina Eaker, Jeff Gordon, and Dante Eaker.

Thanks to direction from the Autism Delaware Golf Committee, running the annual event costs only about 16 percent of the gross revenue. As a result, 84 percent (of the funds raised at this year's event) is being applied to the programs and services needed by

Delawareans living with autism and their families.

The majority of fundraising comes from event sponsors, such as Anheuser-Busch, Aaron's, ING Direct, RoboVision, Crown Royal, Lowe's, NASCAR Foundation, Currency Technics Metrics, and Sprint. *Thank you!*

Smart Cookie Day 2012 Cookies + Advocates = Results

On March 28, Delaware families affected by autism visited Legislative Hall in Dover to ask their legislators to be "smart cookies" by voting for policies that support people and families affected by autism. An annual effort, this year's visit included a press conference that focused on Senate Bill 22 and the critical need for insurance coverage of autism therapies. This news item was picked up by several newspapers and radio stations.

Throughout the afternoon, families visited with their legislators, distributing cookies baked by children with autism, and that evening, Autism Delaware™ held a reception where families and legislators talked in a more relaxed atmosphere. The goal was for families to share their personal stories with the legislators.

As in past years, the Delaware House of Representatives passed a resolution declaring April as Autism Awareness Month. This year, the Senate did as well, and Governor Jack Markell also proclaimed April as Autism Awareness Month.

Thank you to all the families and individuals with autism who advocated on Smart Cookie Day. Keep up the great work by staying in touch with your legislators on the issues that are important to you and your family.

2012 Walk for Autism Neither heat nor rain can stop us!

To everyone who took part in the 2012 Walk for Autism—in the heat on April 21 and the rain on April 22—*thank you so much! You made this event the biggest yet!* Check out these estimates to see just how big an event it was:

- 4,600 Miles covered by walkers**
- 2,300 Walkers**
- 216 Team captains signed up**
- 79 Individuals signed up**
- 238 Online giving pages created**
- 120 Volunteers and staff**
- 5,100 Drinks donated**
- 1 U.S. Senator**

The Hon. Chris Coons led the countdown at the Wilmington walk.

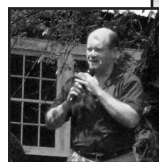


Photo by Chris Clark

To the many people, businesses, and organizations that supported the walk—*thank you!*



Photo by Andrew Zeltz



- A Family Affair
- Bear Glasgow Dental
- Blue Cross Blue Shield of Delaware
- Burns & McBride Home Comfort
- Cape Gazette
- Corporation Service Company
- Delmarva Power
- Diamond State Dentistry
- Eagle 97.7
- Harvard Business Services
- Jolly Trolley

- John F. Kleinstuber & Assoc.
- Next Generation DJs
- Peninsula Dental
- Pepsico
- PNC Bank
- Pyramid Educational Consultants
- Russ Palmer Builders
- Sharp Energy/Chesapeake Cares
- Lorne & Sharon Solway
- Tybout Redfearn & Pell
- Wawa
- Wreckanize Entertainment

And the number everyone wants to know:

\$180,000 Amount anticipated to be raised
The funds you raised for Autism Delaware™ programs will go a long way toward helping Delawareans affected by autism. Great work!

PARENT PARENT

Written by parents for parents

A routine is both a blessing and a hindrance: Once a routine is established, things run pretty well, but the change preceding a new routine can be stressful. Through the years, I have learned that preparation is key. With the transitions to summer vacation and back again to the regular school year, a few tricks help.

For example, I use a monthly picture calendar to show the days of the week to my son Jake and a picture exchange communication system (PECS) to distinguish between “home” and “school.” I also use PECS for vacation days. (These days are simply “beach” because that is usually where we go.) I use the calendar all year, so Jake is aware of the pictures and what they mean. He anticipates what his time will be like and looks forward to special days.

I have also found that advanced notice works better now with Jake than it did when he was younger. I get him ready for a change of routine by telling stories, using PECS, a picture calendar, and a verbal explanation. This process may not work for you, so ask other families living with autism what they do. [For a good resource, attend one of the Autism Delaware™ monthly parent coffee hours listed on the website.]

Not only is Jake’s time spent differently in the summer, but his clothing, of course, is different, too. Preferring a dress code, Jake has “school” clothes and “regular” clothes. I give him a couple of shirts to choose from each day. Once we



Jen Nardo’s son, Jake

get into the summer school routine, Jake reduces his options to his personal favorites. (I do a lot of laundry anyway, so this process works for us.)

With a change of bus driver and aide for the summer, I get everyone’s name up front. When I tell Jake that “Miss So-n-so will be driving you to school,” he feels more comfortable getting on the bus. And if there is a change of location, I either drive Jake past the school or show him a picture that I’ve taken of the school or pulled from the Christina School District’s website. This way, Jake can see where he will be going when he gets on the bus.

I love when his teacher works even part of the summer, but when this doesn’t happen, I use the same approach as I do for a change of bus driver and aide: I repeat the new teacher’s name and talk about how this person will be Jake’s teacher for the summer.

A week in summer school is shorter than a week during the regular school year. To fill the many weeks off in the summer, my husband and I come up with goals for Jake. This year, we came up with two goals. Both can be aided by making PECS and picture calendars a part of the summer’s daily routine.

One goal: Jake will either walk or ride his trike in the morning. As a caraholic, Jake needs to keep moving to keep his weight down. For a system of rewards, Jake is motivated by time on his DVD player. So, my husband and I preface a walk by saying “Take a walk with us, and you will earn your TV time for the day.”

The other goal is to help Jake learn to enjoy the ocean, waves and all. [See the accompanying box for details.] Right now, he enjoys the beach but prefers a body of water without waves. We don’t expect Jake to become a body surfer; we only want him to feel comfortable enough to enjoy himself.

As you enjoy the summer, remember that change is stressful to everyone. As a responsible parent, you prepare your child to learn to live with change. You can either anticipate meltdown after meltdown or admit that your child is confused and scared—and handle it. With a consistent process that works for you and your child, change will become a norm.

For Jake, the end of the school year is now the beginning of his summer routine. And he will take this lesson with him into his life as an independent adult in the community. This is definitely a blessing!

—Jen Nardo

Teaching Jake to enjoy the ocean

According to Jen Nardo, the process will probably take all summer. Because Jake will only wade into the water up to his calves, the goal is to increase the amount of time spent in the water and the water’s depth. The plan involves play and lots of patience: Nardo and her husband will run in the surf and play chase with Jake while gradually increasing the time and depth. “As the temperatures of the air and water rise over the summer,” notes Nardo, “they will naturally help my plan. As time goes on, I will add sitting in the surf and playing with balls and other water toys. If needed, I’ll use our system of rewards: ‘Get in the water, and you will earn your TV time for the day.’”

Nationally recognized advocate headlines this year's inclusion conference

The 18th Annual Inclusion Conference was held on March 15, 2012, at the Sheraton Dover Hotel & Conference Center. Entitled *Inclusion: It Should Just Be How We Roll*, the conference was attended by more than 600 teachers, administrators, and community leaders, including M. Kathleen DeNight, who attended with help from an Autism Delaware conference stipend. This is her report.

For info on the Autism Delaware™ conference stipend, visit www.delautism.org.

The keynote speaker at the 18th Annual Inclusion Conference was author and advocate Jonathan Mooney. The founder of Project Eye-to-Eye (a mentoring and advocacy non-profit for students with learning differences), Mooney did not read until he was 12 years old, yet his challenges in school did not prevent him from graduating with an honors degree in English literature from Brown University. Mooney is the winner of the Truman Scholarship for graduate studies in disability studies and social change. His advocacy work on behalf of all students with disabilities

is recognized nationally. You can discover more about his story and his work at www.jonathanmooney.com.

Mooney is an attention-grabbing, enthusiastic young man with a viewpoint that is necessary, yet often absent from the conversation on what inclusion means. As keynote speaker, he shared many of his experiences as a child in special education and what he presently encounters through his advocacy work and the mentoring of students with learning differences. He also articulated his vision of cultural change: making communities that nurture differences based on motivation, intelligence, and behavior (as opposed to marginalization).

According to Mooney, the foundational belief that drives an inclusive environment requires a broader and more expansive definition of "smart," "well-behaved," and "motivated." Currently, the narrowing definitions of intelligence, motivation, and behavior threaten the inclusive effort, and we need to fight that trend. For example, correlating intelligence with the ability to read omits all the other markers of intelligence from the conversation. Instead of asking "How smart is that kid?" we should be asking "How is that kid smart?"

In Mooney's afternoon session, he expanded on his keynote address by defining the skills needed by different types of learners as well as the environment needed to provide a true learning opportunity. According to Mooney, the learner's brain needs to be reframed so it can develop a self-concept. And self-advocacy is required to make learners knowledgeable enough to communicate how they learn. The key component in Mooney's proposal is character development or a set of character-oriented behaviors that develop resiliency, willpower, and self-control.

The environment necessary to implement Mooney's vision cannot be a one-size-fits-all way of teaching and learning. Mooney proposed replacing the content creed that measures progress with a stress on the learning process. Also, less importance needs to be placed on standardized testing, disabling environments need to be restructured, assistive technology needs to support classrooms, workstations need to replace desks, and educators need to become facilitators of learning.

As an autism advocate, I found Mooney's talks worthwhile, and I can't wait to see if and how his proposal is tried around the state. If I measure his environment of self-concept against my own "very special education" with the Sisters of the Immaculate Heart of Mary, I break out in a cold sweat: Am I to have my son learn the way I did or raise him for a world he can live in? These are two entirely different worlds!

Welcome new members!

Harry Curriden
& Melanie Gaglio
Robert Dayton
George Ecker
Peter & Lisa Galasso
Greg & Sharon Glovick
Alison Hoffman

Patricia Lord
Jamie L. McAndrews
Jessica McDonald
Randy & Crystal Perry
Martin Previtiera
Christina Roberts
Rhonda Tuman
Tina Wilkins

Did you know?

Autism Delaware™
now offers
clinical services.

For details, visit
www.delautism.org.

Or call (302) 224-6020.

Honoring Autism Delaware's outstanding volunteers

Of the many volunteers acknowledged by Autism Delaware™ for exemplary effort in 2011, Patricia Quinn and Bill Dickhart of Wilmington and Betty Grace Eskridge



Front row (L to R): Volunteers Patricia "Trish" Quinn, Luci Szymanski, and Karen Tuohy. Back row: Autism Delaware Executive Director Theda Ellis, Frank Andrews, Bill Dickhart, Betsy Fisher Gray, Autism Delaware President Marcy Kempner, and Betty Grace Eskridge.

of Bridgeville received special awards at the annual volunteer recognition dinner on March 30 at the Turn 2 Chalet of Dover International Speedway. And five received an Outstanding Autism Delaware Volunteer award. They are Susie Kelly of Laurel; Luci Szymanski of Newark; Frank Andrews, Betsy Fisher Gray, and Karen Tuohy of Wilmington; and Chicago-based software company Scoutware.

"These volunteers provided much-needed help during social outings and fundraising events and provided it often throughout the year," says Theda Ellis, Autism Delaware's executive director. "And Scoutware donated the use of its software, which completely changed the way we interact with people via email. Plus, Scoutware created graphics for our golf event, auction, and the volunteer recognition dinner."

New this year, the Autism Delaware Judy Hedrick Award acknowledges a volunteer who provided extraordinary support in the autism agency's Newark or Milton office. Named for long-time volunteer Judy Hedrick—a grandmother who not only volunteered in the Newark office but also managed volunteers for the Walk for Autism, Drive for Autism Celebrity-Am Golf Outing, and Auction for Autism—the first award was given to Patricia "Trish" Quinn.

Quinn began work in the Newark office as an intern through Dawn Career Institute and stayed as a volunteer for nine months after graduating. "A major reason for naming Trish for this award is the huge task she took on," notes Ellis, "combining information from our merger with the Lower Delaware Autism Foundation into Autism Delaware's new database. This work required a massive amount of time, an eye for detail, and the patience of a saint. Trish definitely went 'above and beyond the call of duty.'"

The Autism Delaware Noel Perry Smith Award for Outstanding Employer was awarded to Kirkwood Highway businessman Bill Dickhart. In addition to employing people with

autism spectrum disorders, Dickhart helps increase their employability by working with support personnel from Autism Delaware's adult services program, Productive Opportunities for Work & Recreation™ (POW&R™). "Bill 'gets' autism," says Ellis, "and is willing to try anything to support his employees so they do a better job and can move forward in life."

Also recognized for effort on behalf of Delawareans with autism, Betty Grace Eskridge was named the Outstanding Leader in the Community. "Betty has a unique understanding of 'fun-raising,'" notes Ellis. "She leads a team in southwestern Delaware that combines motorcycles, a bake sale, a silent auction, and lots of laughs. Recently, she added her determination, dedication, and drive to our development committee."

Party time!



On Saturday, February 25, Autism Delaware™ hosted its first winter dance at the Cape Henlopen Elks Lodge. Students, aged 14–21 and living in Kent and Sussex Counties, were able to invite one guest each. Cape Henlopen High School's Best Buddies were also invited to join the fun.

"The kids danced the night away," says DJ Slim Money (also known as Robert Gordy). "My heart was touched to see everyone have such a good time. I will continue to support Autism Delaware with any event possible."

"For a first-time event, the turnout was good," notes Amanda Jackson, Autism Delaware's event coordinator. "Just like you and me, students affected by autism sure do know how to party!"

The parents who chaperoned the evening were thankful for the social event, noting that they would like to see more social events for older children with autism spectrum disorders (ASDs).

Jackson organized the winter dance with parent Susan Patel. Would you like to create more social situations for older children with ASDs in southern Delaware? Email amanda.jackson@delautism.org.

INSIDE Autism™ Delaware

Growing into the role

public services) as well as in direct services. Autism Delaware is also continuing to prepare for our transition into new management following the executive director's retirement in December 2012.

To improve information and services, Autism Delaware has updated the website and parent package, and now, we are working to expand programs and services. In turn, we've needed more help and office space. In addition to a bounty of outstanding volunteers—See the article on page 6—Autism Delaware added staff, including a new associate director, Brian Hall, M.S.W.; a receptionist and office assistant for the Newark office, Kim Rosebaum; and a clinical director, Susan Peterson, Ph.D., BCBA-D. (For more on Peterson and clinical services, see the April–June 2012 issue of *The Sun*, or visit www.delautism.org.)

Shifting management roles

In conjunction with Theda Ellis's upcoming retirement, the Autism Delaware Board of Directors named Associate Director Teresa Avery to the position of executive director effective January 2013. To prepare for her move into the position, Avery will add executive director-level management and fiscal responsibilities to her development and communications work starting this July. She will also be in charge of developing Autism Delaware's next strategic plan, which will carry the organization through 2018.



Brian Hall

Assuming responsibilities as Autism Delaware's new associate director, Brian Hall joined the staff in June. New to Delaware, Hall most recently worked as the campus director for Julia Dyckman Andrus Memorial Inc. (Yonkers NY), overseeing the residential and day treatment programs for 153 children (kindergarten–ninth grade) with moderate to severe emotional and behavioral problems. Hall will also assume Ellis's advocacy and programmatic responsibilities, oversee all Autism Delaware programs and services, and develop a range of community living services for adults with autism.

In July, Ellis enters the final phase of her step-down to

retirement. At that time, she will begin working only three days a week. Assisting Brian Hall and Teresa Avery as they transition into their new roles, Ellis will work with Hall to plan and develop future direct services, and on strategic planning with Avery.

"Autism Delaware is fortunate to have this transitional luxury that will ensure a smooth step into the future," says Autism Delaware Executive Director Theda Ellis, "and we are really pleased to announce our new and powerful management team."

Welcome, Kim Rosebaum

Kim Rosebaum accepted the newly created position as the Newark office's receptionist and office assistant in



January and instantly made a name for herself as the helpful, hospitable voice you hear when you call (302) 224-6020. The Wilmington resident comes to us with experience at the Parent Information Center (PIC) of Delaware and JPMorgan Chase.

Rosebaum also supports Autism Delaware's fundraisers and POW&R™ services and will be working with Susan Peterson in clinical services.

More office space in Newark

In April, Autism Delaware's second-floor neighbors in Newark moved out, leaving floor space to accommodate our growing needs. After renovations, private work areas are now enjoyed by a number of staff, including Autism Delaware's executive, associate, and clinical directors, resource specialist, and POW&R director. Also, space has been assigned especially for volunteers.

POW&R in Sussex

Autism Delaware's adult services are now available in Sussex County as well as in New Castle and Kent. Lana Short has been hired to support the southern Delaware POW&R coordinator, Melissa Martin.

"With POW&R services in Sussex this year," notes Ellis, "Autism Delaware exceeds all the expectations of the merger with the Lower Delaware Autism Foundation."



Lend a helping hand!

Autism Delaware is a small non-profit that relies on volunteers to get things done. Volunteer opportunities are available in both offices, various programs, and at events.

If you would like to help, either send an email of interest to volunteers@delautism.org. Or call (302) 224-6020.

Federal student aid



“The provision of federal student aid to students with intellectual disabilities is an important step toward transitioning them not only to post-secondary education but to the world of work and independent living,” write Ernst O. VanBergeijk, Ph.D., M.S.W.,

and Paul K. Cavanagh, Ph.D., M.S.W. “Help transform this well-kept secret to common knowledge by telling parents of students with intellectual disabilities and their advocates of this ‘new’ opportunity” (*Federal Student Aid for Students with Intellectual Disabilities: A Well-kept Secret? Parenting Special Needs, May/June 2012*: p.64).

What is this new opportunity?

The U.S. Congress’s reauthorized version of the Higher Education Opportunities Act (HEOA) now makes post-secondary education possible for students with autism spectrum disorders—through federal student aid.

To qualify for federal student aid, the eligible student must be enrolled in a U.S. Department of Education-approved comprehensive transition and post-secondary (CTP) program. For a list of approved CTP programs, visit <http://studentaid.ed.gov/PORTALSWebApp/students/english/CTPProgramList.jsp>.

To be eligible, a student must have an intellectual disability as well as be eligible for a free, appropriate public

education under the Individuals with Disabilities Education Act (IDEA). The student needs documented proof of an intellectual disability, but does not need to have a high school diploma or to pursue a degree or certificate.

For requirements plus a free application for federal student aid
<http://www.fafsa.ed.gov/>
(800) 4-FED-AID
[1-800-433-3243]

CALENDAR of EVENTS

July

- 10**—Parent Coffee Hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 P.M.
- 11, 18, 25**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Heidi Mizell at heidi.mizell@delautism.org. Or call (302) 224-6020, ext. 205.
- 11**—Parent Coffee Hour. Arby’s. 1155 Highway One. Suite 5018. Lewes. 9:00 A.M.
- 13**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 P.M. *Registration:* delautism@delautism.org.
- 14**—Sensory friendly movie: *Ice Age 4*. Carmike Cinemas in the Dover Mall. 1365 N. DuPont Hwy. Dover. 10:00 A.M.
- 27**—Teen/Tween game night. Autism Delaware Milton office. 6:00–7:45 P.M. *Registration:* Dafne Carnright @ (302) 644-3410.

August

- 1, 8, 15, 22, 29**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Heidi Mizell at heidi.mizell@delautism.org. Or call (302) 224-6020, ext. 205.
- 12**—Summer beach picnic. Cape Henlopen State Park. Main Beach Pavilion. 15099 Cape Henlopen Dr. Lewes. 12:00–3:00 P.M. *Reservations:* (302) 644-3410 or (302) 224-6020.
- 14**—Parent Coffee Hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 A.M.
- 15**—Parent Coffee Hour. Holiday Inn Express. 1780 N. Dupont Hwy. Dover. 9:00 A.M.
- 17**—Teen/Tween game night: Autism Delaware Newark office. 6:30–8:30 P.M. *Registration:* delautism@delautism.org.
- TBD**—Teen/Tween game night. Autism Delaware Milton office. 6:00–7:45 P.M. *Registration:* Dafne Carnright @ (302) 644-3410.

September

- 5, 12, 19**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 11**—Parent Coffee Hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 P.M.
- 14**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 P.M. *Registration:* delautism@delautism.org.
- 18**—Parent Coffee Hour. Arby’s. 1155 Highway One. Suite 5018. Lewes. 9:00 A.M.
- 22**—Skating party.
Milford Skating Center Roller Skating Rink. 1 Park Av. Milford. 5:30–7:30 P.M.
Christiana Skating Center Roller Skating Rink. 801 Christiana Rd. Newark. 5:15–7:15 P.M.
- 28**—Blue Jean Ball. Nassau Valley Vineyards. 32165 Winery Way. Lewes. 7:00–11:00 P.M. *Reservations:* (302) 644-3410 or www.delautism.org.
- TBD**—Teen/Tween game night. Autism Delaware Milton office. 6:00–7:45 P.M. *Registration:* Dafne Carnright @ (302) 644-3410.

Teen/Tween game night

For 9–19 year olds
with Asperger's syndrome

Place: Autism Delaware™
Newark office

Dates: July 13
August 17
September 14

Time: 6:30–8:30 P.M.

Cost:
\$30 per season
Must be paid
at registration

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

Summer 2012 season

For 9–14 year olds with
Asperger's syndrome

Place: Autism Delaware™
Milton office

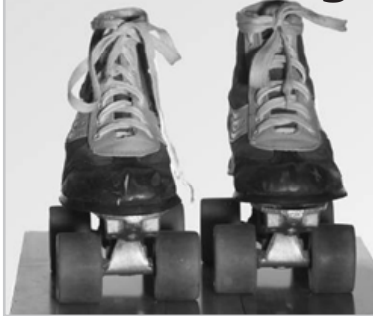
Dates: July 27
August TBD
September TBD

Time: 6:00–7:45 P.M.

Cost:
\$10 per season
Must be paid
at registration

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

Roller skating!

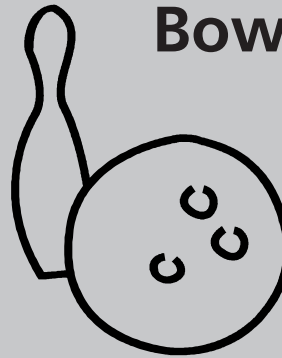


September 22

5:15–7:15 P.M.
Christiana Skating
Center Roller Skating
Rink, 801 Christiana
Rd., Newark

5:30–7:30 P.M.
Milford Skating Center
Roller Skating Rink,
1 Park Av., Milford

Bowling night



Every Wednesday
5:30–7:00 P.M.

Bowlerama
3031 New Castle Av.
New Castle, Del. 19720-2297

See the Calendar of Events
(p. 8) for registration info.

Mark your calendar!

Enjoy a special evening of fun,
food, and entertainment while
supporting the many statewide
programs and services provided
by Autism Delaware.



Friday, September 28

Blue Jean Ball
7:00–11:00 P.M.
Nassau Valley Vineyards
32165 Winery Way, Lewes



Reservations: (302) 644-3410
www.delautism.org

Saturday, November 10

14th Annual Auction for Autism
7:00–11:00 P.M.
DuPont Country Club
1001 Rockland Rd., Wilmington



Reservations: (302) 224-6020
www.delautism.org

Your child's education Continued from page 1

ized needs. To this end, the IEP team should create a program with these core areas in mind:

- the student's need for improved verbal and communication skills
- the student's skill with social interaction
- the student's sensitivity to environmental stimuli
- the student's response to change
- the student's ability to modify repetitive behavior and movements and the need for positive behavioral interventions
- the need for a functional behavioral assessment (FBA) that matches the intensity level of the student's repetitive behavior and movements

"Ideally, all interventions should be presented as an educational need," write Melvin L. Morse, M.D., F.A.A.P., and Sue Moniz, R.N., in *IEP Planning and Educational Recommendations for Children with Asperger's and High Functioning Autism*. "It is the responsibility of the parents to educate and convince the school district that [their] child has unique educational needs."

Contact Autism Delaware for more information or help with your child's IEP. In northern Delaware, call Heidi Mizell at (302) 224-6020, ext. 205. Or send an email to heidi.mizell@delautism.org. In southern Delaware, contact Dafne Carnright at (302) 644-3410. Or email her at dafne.carnright@delautism.org.

Your parental rights

Do you remember that little booklet your child's individualized education program team (or IEP team) has been offering you at every IEP meeting?

It's called **Procedural Safeguards**. According to Dafne Carnright, a parent mentor and the Autism Delaware southern Delaware service coordinator, you should keep a copy and read it (despite the going joke that reading it will help you fall asleep). Make sure you have the most recent edition, dated May 2012; you can tell by the date on the front. Then, become familiar with it because it describes your parental rights as established by the Delaware State Code and Delaware's Administrative Code.

For example, did you ever wonder how to proceed if you don't agree with a portion of the IEP presented by your child's

school? The booklet can help you understand your options by explaining your rights. Here are a few basics:

- The child has a right to a free, appropriate public education (FAPE) designed to meet his or her specific needs.
- Parents are a part of the child's IEP team; therefore, parents are part of the decision-making process and have the right to give input and ask questions. Parents can also invite others of their choosing (such as an aunt, therapist, or advocate) to their child's IEP meetings.
- Parents have the right to take the IEP home and review it for 10 days before signing it. Parents also have the right to sign "agree" or "don't agree" on the IEP document.



Bridget, Karen, and Sean Tuohy at home

- Parents have the right to request an IEP meeting at any time.
- Parents have the right to observe their children's educational programs, which means parents can observe their children's classrooms and their time spent in the community. Usually, parents need to request this time in advance.
- Parents have the right to request that a psycho-educational evaluation be completed by the school, and the school has to pay for the tests. If parents don't agree with the evaluation, they have the right to request an independent evaluation, and the school has to pay for this evaluation also—unless the school district wants to take legal action to prove that its evaluation was appropriate.

tion also—unless the school district wants to take legal action to prove that its evaluation was appropriate.

- Parents have the right to ask that the evaluation scores be presented in ways they can understand, such as standard scores, percentile ranks, and grade and age equivalents. The evaluator can help with this item.

For more on parental rights, read *Individualized education program: What you may not know—but should*, by Marie-Anne Aghazadian, executive director of Parent Information Center (PIC) of Delaware, Inc. This article can be downloaded from the Autism Delaware website—www.delautism.org—under Autism Resources, Learning Links, and Autism Articles.

You know your child depends on you. And you are your child's best advocate. So, if you don't have a copy of **Procedural Safeguards**, check out the actual code it's based on. You can find it on the State of Delaware website at <http://regulations.delaware.gov/AdminCode/title14/900/926.shtml#TopOfPage>.

Your parental rights transfer to your child when he or she turns 18—unless you establish legal guardianship of your child. Consider whether guardianship is needed for your child before he or she turns 18. For more, see the cover story of the January–March 2012 issue of *The Sun*.

Looking to the future



Delcastle High School freshman Joey Principe and Katina Demetriou, Autism Delaware's POW&R director, enjoyed this year's Transition Conference in Dover.

This year's Transition Conference was held April 3 at the Sheraton Dover Hotel. Designed for people who are interested in the issues faced by students with autism as they transition into the adult world, the conference caused attendees, like 15-year-old Joey Principe, to think about their futures.

"It was a fun day to learn about growing up and getting a job," says Joey, the son of Autism Delaware's event coordinator, Deanna Principe. "I don't have a job right now. But I like to draw cartoons and do animation on my com-

puter, so I think maybe I would like to do something like that as a job.

"I worry about driving a car," adds Joey. "I'm not sure I can do that. My parents say that I will learn though. I didn't see any information about driving at the conference.

"The workshop I liked best," continues Joey, "was the one when the man with Asperger's told stories about his life and said that, even though you have autism or Asperger's, you can get a job and be successful. I hope that's true because I want to be rich."

What do the new numbers for autism mean? Continued from page 1

have improved significantly, adults with ASDs are more likely to be misdiagnosed.

Appropriate diagnosis for individuals with Asperger's syndrome is even more problematic. Asperger's is considered a relatively new disability. It wasn't even known in the U.S. until Hans Asperger's work was translated into English and incorporated into the World Health Organization's diagnostic manual and the **Diagnostic and Statistical Manual of Mental Disorders (DSM)** in the early 1990s. Only in the past 10 years has Asperger's syndrome become more commonly understood; thus, we have generations of psychologists, psychiatrists, teachers, and school counselors who have not been trained to recognize and treat Asperger's syndrome.

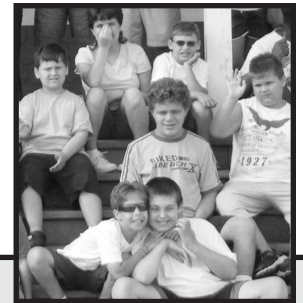
So what does the increase in numbers mean?

It means an increasing impact on all systems (publicly funded services across different agencies)—and the need for advocacy to jump to the top of the priority list. Children still need to leave school with the practical and social skills to navigate the adult world of work and relationships. With more children needing these skills, systems must be using evidence-based practices and expanding their capacity to serve children and adults across the spectrum through better staff education and training. And the schools should ensure that students either graduate into jobs or are prepared to meet the challenges of post-secondary education.

We also need services and agencies to collaborate more effectively with each other so that the individual living with autism may have access to social services, mental health services, housing, independent living, and whatever else he or she needs. After all, people with diabetes go to diabetes specialists—not the DD case manager. Why shouldn't people with autism seek mental health services from mental health agencies?

In sum, our job as advocates is to expand not only the capacity of Delaware's systems to better meet the needs of

people living with ASDs, but also to expand to meet the growing population and the growing need. The future of our children depends on it.



Consider these numbers:

152 That's the number of public school students who have autism as reported in 1991 by the Delaware Department of Education (DOE).^a

982 That's the number of public school students who have autism as reported in 2010—a 546 percent increase over 19 years. Nationally, autism has increased by about 600 percent over the past 20 years, so Delaware appears to be on track with national data.^b

From information received in March 2012, the Delaware Division of Developmental Disabilities Services (DDDS) reports that 565 individuals with autism registered for services:

- 269 adults with autism
- 218 children with autism
- 32 adults with Asperger's syndrome
- 46 children with Asperger's syndrome

^a The DOE can report only those children in the public school system who have an educational classification of autism.

^b In Delaware, the DOE and local districts do not typically accept a medical diagnosis of autism; thus, these numbers include only students who have an educational classification of autism. We also know that children with Asperger's syndrome are not likely to have a correct diagnosis—or any diagnosis at all—so we suspect that these numbers do not reflect all our students who are on the spectrum.



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My membership fee is \$ _____
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Total amount enclosed \$ _____

Becoming a silver, platinum, or lifetime member will make you a part of a select group of individuals who have demonstrated special leadership and a commitment to helping us meet our mission. As a leader in the support of autism services and research, you will receive special recognition in our newsletter or other materials.

Yes! Please add my name to the mailing list to receive *The Sun* through DAP distribution. (This option is only for families who do not receive *The Sun* through DAP distribution.)

I am a: Parent Family member Service provider Educator Medical professional Individual with autism Other (Please describe): _____

Name(s): _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (h) _____ (w) _____ Email: _____

I am a new member. I am renewing my membership.
 Individual \$20 Family \$25 Professional \$50 Silver \$100 Platinum \$300 Lifetime \$500

Enroll me in the following category:

Annual membership application