

The Sun

Newsletter

July–September 2016

Inside this issue

Senate passes ASAP 3

Inside Autism Delaware 4–7

From the desk
of Autism Delaware’s
resource coordinator. 8

Do you want to play?. 9

Observing your child
in the classroom 10

Book brings donations 11

PARENT PARENT

Teaching your child’s classroom about autism

This article headlines two parents of children on the spectrum. Mother of seven-year-old Casey, Cory Gilden is also a former elementary school teacher, a long-time contributor to *The Sun*, and a PhD candidate studying the relationship between home and school. Starting below, Gilden shares her multi-faceted perspective for introducing a child to the classroom.

On page 8, this article is expanded by the parent of 18-year-old Jake Nardo. A long-time autism advocate and contributor to *The Sun*, Jen Nardo explains her decisions to disclose the fact that her son has autism and how much information to share with his classroom.

Introducing your child to the classroom

The current trend toward inclusion, begins parent Cory Gilden, invites children with autism into the regular-education classroom to learn alongside their neurotypical peers. These students may notice that children with autism do things a little differently. What they may not know is why.

Introducing your child with autism to the classroom, notes Gilden, could create an understanding and helpful environment. Because each child is unique—as well as the classroom situation—many aspects can be considered if you choose to introduce your child to the class.

Your child’s self-awareness

Some children do not know they have autism or what this means, states Gilden. If you haven’t had this talk with your child yet, it may be best for your child to be out of the room when the rest of the class discusses autism.

If your child does know he or she has autism, you may want to first make sure that your child feels comfortable with you talking about it with the class.

If your child is comfortable with an introduction, ask if he or she wants to help with the presentation.

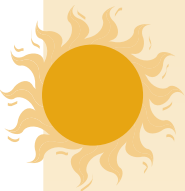
Who should present

Comfort levels may vary when it comes to talking to a class about autism, continues Gilden. Sometimes, a parent may not be the best person to do the presentation or activity. Instead, a parent may prefer to work with the teacher or a guidance counselor in developing a way to deliver the topic and introduce a child to the class. While parents may know their children best, an educator is often more familiar with what is age appropriate and how the class would best receive the information.

Whoever presents the information, parents should meet with educators ahead of time to ensure that everyone feels comfortable with the topic.

When to present

Some parents may want to present as early as possible in the school year so the class understands the child’s strengths and weaknesses from the beginning. Other parents may want to wait a month or two to see how the students react to a new classmate on the spectrum. And still others may choose to wait until autism awareness month in April to do a presentation because the school may already have activities devoted to teaching the students about autism at that time.



Our mission

To help people and families affected by autism spectrum disorder (ASD)



Autism Delaware™

Newark

924 Old Harmony Rd.
Suite 201, Newark DE 19713
Phone: 302.224.6020

Dover

c/o Dover Downs
1131 North Dupont Hwy., Dover DE 19901
Call for on-site appointment:
302.224.6020 or 302.644.3410

Lewes

17517 Nassau Commons Blvd.
Unit 1, Lewes DE 19958
Phone: 302.644.3410

Email

delautism@delautism.org

Website

autismdelaware.org

Family support

Kent and Sussex Counties

Dafne Carnright
Family service coordinator
dafne.carnright@delautism.org

New Castle County

Heidi Mizell
Resource coordinator
heidi.mizell@delautism.org

Officers

President

Pete Bradley
pbradley@doverdownsslots.com

Vice president

Marie-Anne Aghazadian
elisa945@gmail.com

Secretary

John Fisher Gray
john.f.gray@dupont.com

Treasurer

Jeff Flanders
jflanders@midcoastbankonline.com

The Sun

A publication of Autism Delaware

Editorial committee

Carla Koss
Ann Athas Cory Gildea Heidi Mizell
Liz Carlisle Gail Hecky Jen Nardo
Dafne Carnright

Autism Delaware™, POW&R™, Productive Opportunities for Work & Recreation™, and the Autism Delaware puzzle-piece logo are trademarks of Autism Delaware Inc.

On Liam's lessons

I am thrilled and honored to be named president of the 2016 Autism Delaware Board of Directors. I have been very fortunate to serve on the board under the leadership and vision of the outgoing president, Marcy Kempner. I admire Marcy's passion and commitment to advocating for people with autism and their families. Marcy is an inspiration to me.

As a family with a young son with autism, my wife and I frequently turned to Autism Delaware for guidance. We were as involved as we could be in our topsy-turvy lives and vowed to do more when time allowed. Then in 2007, our son Liam passed away suddenly from a seizure. The darkness in our lives could be brightened only by the opportunity to grow his legacy. Autism Delaware has given our family the opportunity to parent Liam's legacy.

One of the key lessons I learned from my son—My family calls them "Liam's lessons"—was that an individual on the spectrum can do and accomplish more than many people think. And I see this lesson in action at my company every day. I work at Dover Downs Hotel & Casino where 11 individuals are now employed in a variety of capacities as part of Autism Delaware's adult employment program, which is commonly known as POW&R (or Productive Opportunities for Work & Recreation). From my company's perspective, we have gained highly productive, reliable employees who make a difference—

not only to our business but also in their own lives. I have heard and seen for myself countless examples of how these 11 individuals are achieving various milestones and progressing in their respective careers.

Other POW&R benefits include greater awareness, education, and acceptance of individuals on the spectrum by the general public. We see this light going on every day at Dover Downs as well as at all of the companies that employ POW&R participants. I experience quiet gratification every time a member of the supervisory team learns a Liam's lesson and now defines a person by his or her ability instead of the disability.

During my tenure as an Autism Delaware board member, I have come to admire the tenacity and vision of the Autism Delaware family. They provide the depth of service that touches and changes lives. This barometer truly is how a service organization should be measured.

As we continue our endless journey, the Autism Delaware team is available as a resource for you. And from you, we need your ideas. Your time as a volunteer is also needed. Come join us, and help make a difference in our world and yours.



Pete Bradley
President

Pete Bradley

A service of Autism Delaware



Katina Demetriou, director
katina.demetriou@delautism.org
Bus: 302.224.6020 Ext. 202 **Cell:** 302.824.2252

Melissa Martin, assistant director
melissa.martin@delautism.org
Bus: 302.644.3410 **Cell:** 302.824.9710

Kim Rosebaum, vocational administrative assistant
kim.rosebaum@delautism.org
Bus: 302.224.6020 Ext. 214

Senate passes ASAP

On April 14, many of Delaware's elected officials currently seated in Legislative Hall greeted 30 of their constituents. As participants in Autism Delaware™ Smart Cookie Day, these constituents promoted the passage of the Autism Services Advancement Package. Called ASAP, for short, the package consisted of senate bills 92 and 93—and both were passed unanimously.

Sponsored by Del. Sen. Margaret Rose Henry (D-Dist. 2) and Del. Rep. Earl G. Jaques (D-Dist. 27), SB92 amends the current Delaware Code so the office of the statewide director of the Delaware Autism Program (DAP) can offer services to children on the spectrum who attend all Delaware schools, not only the current six DAP programs.

And SB93 establishes the Delaware Network for Excellence in Autism. This resource allows the director's office to deploy training and technical assistance to state agencies, schools, and organizations to provide services and support to individuals and families affected by autism.

When this newsletter went to the printer, ASAP had been assigned to the Delaware House of Representatives Appropriations Committee for funding.



Autism advocate Melissa Stansell, on the floor of the Delaware Senate, explains her son's needs as a full-time student in an autism-supported classroom and helps convince the senators of the dire need for the ASAP legislation.

Thanks for the kickoff!

A big *Thank you* goes to Tyler Anaya. A parent and long-time Autism Delaware supporter, Anaya worked with the Levy Court so the commissioners could proclaim April as autism awareness month in Kent County during a ceremony on March 16.

This proclamation served as the kickoff for Autism Delaware's unprecedented "30 days of awareness" campaign. More than 80 fundraising events, programs, and information tables took place statewide in April!

All information provided or published by Autism Delaware is for informational purposes only. Reference to any treatment or therapy option or to any program, service, or treatment provider is not an endorsement by Autism Delaware. You should investigate alternatives that may be more appropriate for a specific individual. Autism Delaware assumes no responsibility for the use made of any information published or provided by Autism Delaware.

Proclaiming awareness

On Smart Cookie Day, Delaware state senators and house representatives proclaimed April as autism awareness month in Delaware. And Governor Jack Markell made a proclamation from his office in Legislative Hall.

Among the many autism advocates in Legislative Hall on April 14, Autism Delaware office assistant Kyle Bryan served as a Smart Cookie Day team leader. Visiting state legislators, Bryan related some of his struggles as an individual on the spectrum as well as some of his accomplishments.

Bryan added that he looked forward to the passage of the Autism Services Advancement Package (ASAP) because it would bring much-needed benefits to the autism community.

Later in the day, Bryan repeated his presentation for Gov. Markell in front of the entire contingent of autism advocates, including parents of children on the spectrum, representatives from the Delaware Department of Education, Girl Scout Troop #1027 from Magnolia, and the University of Delaware Center for Disabilities Studies.

"When I finished my speech," smiles Bryan, "I got the biggest surprise of my life: a standing ovation, cheers, and applause. And Governor Markell told me that, in his years, he had never heard a speech given with such clarity."



Delaware Gov. Jack Markell displays his proclamation with Samuel DeNight, son of long-time autism advocate Kathy DeNight.



Autism advocate Kyle Bryan shakes hands with Gov. Markell as Autism Delaware Board of Directors president Pete Bradley looks on.

INSIDE Autism[™] Delaware

Autism conference

Reduced-price tickets available

Now available is a reduced rate for the \$145 cost to attend the autism conference sponsored by Devereux in partnership with Autism Delaware.

For family members, a limited number of tickets are available at \$95 per person. (To support this reduced price, Autism Delaware supplied the funds usually set aside for year-round workshop and conference stipends.)

An early-bird rate of \$125 is available through September 2 for physicians, psychologists, teachers, and social workers looking for CEUs and CMEs. For details, visit devereux.org/AutismA-Z.

About the conference

Organized especially for families affected by autism and the professionals who serve them, the one-day autism conference takes place September 30, 9:00AM–4:30PM, at the Chase Center on the Riverfront in Wilmington.

Called *Autism A–Z: Beyond the Puzzle*, the first-time conference offers a variety of interactive workshops. Attendees can customize their learning experience by choosing workshops focused on education, social skills, nutrition, medication, housing, technology, functional behavior assessments (FBAs), and more.

Two autism experts will deliver keynote addresses:



Deidre L. Donaldson, PhD, ABPP, is chief clinical officer of The May Institute, “one of the largest and most well-respected providers of services and special education schools for children and adults with autism and other special needs in Massachusetts and in the U.S.” (http://www.mayinstitute.org/about/our_organization.html). Donaldson has also served as director of The May Institute’s pediatric psychology services as well as director of the Fernandes Center for Children

and Families at Saint Anne’s Hospital in Fall River, Massachusetts (http://www.mayinstitute.org/about/executive_leadership.html?bio=706).

Peter F. Gerhardt, EdD, is executive director of the EPIC School in Paramus, New Jersey, whose mission is to provide “individuals with autism with a scientifically-validated education and treatment” (<http://www.epicschool.org/about-epic>). Gerhardt has worked in educational, employment, residential, and community-based settings and has more than 30 years’ experience using applied behavior analysis (ABA) with individuals on the spectrum. He is also the founding scientific council chair of the Organization for Autism Research (<http://www.epicschool.org/about-epic/epic-staff>).



For more information or to register for the conference, visit devereux.org/AutismA-Z.

POW&R[™] dishes a winner

What dish received the red ribbon in The Salvation Army–Delaware 2016 Souper Bowl?

The chicken corn chowder made by Nick Graham, Danny Kee, Carol Luff, Malcolm McKelvey, Drakshya Mishra, Craig Montanaro, and Ellantae Swain!



Clip Art

All seven winners participate in Autism Delaware’s adult employment program. Known as Productive Opportunities for Work & Recreation[™] (or POW&R, for short), the program was recognized in 2013 as one of 10 effective programs nationwide for adults on the spectrum.

“POW&R beat out eight other competitors,” says direct support professional Tom Spittel of the Souper Bowl competition, “and our soup was a hit. This was all due to the work of our participants and the donation of ingredients by the Cedars Church of Christ in Prices Corner. The event went over well, and POW&R was invited to compete again next year.”

Community survey provides feedback

Plans made for annual survey

Earlier this year, Autism Delaware collected information from our community through an online survey. The purpose was to help understand community needs and how Autism Delaware programs and services are helping.

The survey was answered by 112 respondents. They provided feedback, appreciation, and suggestions for improving areas as diverse as legislative advocacy, agency communications, family support programming, and recreational opportunities.

Autism Delaware’s leadership is taking a close look at all the survey responses and, as a result, where changes may be made for the future.

A similar survey will be offered again next year. The plan is to collect responses annually so that Autism Delaware can see how we are doing over time.

For more information about the survey, visit autismdelaware.org, or contact executive director Teresa Avery at teresa.avery@delautism.org.

Breaking records

Organizers of the 2016 Walk for Autism know that at least 2,000 people faced the wind and rain that arrived during the Wilmington leg of the statewide event because the event's title sponsor, Horizon Services, handed out a full supply of rain ponchos—and ran out!

Nothing could deter the tenth anniversary celebration in Fox Point State Park on April 23. To mark the anniversary, the walkers took part in the world's longest high-five chain. Walk organizers set up the pre-walk path to meet the criteria for entry into *The Guinness Book of World Records*.

"We also doubled the high-five chain because it's a 10-year celebration," notes Autism Delaware events manager Deanna Principe. "We didn't have a drone because of the wind, but we have video to submit. And I'm pretty sure we broke the record."

Also new for the anniversary celebration, NASCAR driver Daniel Hemric made a guest appearance with his #19 Brad Keselowski Racing Ford with the autism puzzle piece.



This year's grand marshal in Wilmington was six-year-old Brenna Vendrick. The Old State Elementary first grader loves going to the beach, walking the boardwalk, and swimming in the ocean.

"Brenna's favorite thing is mermaids," notes her mother Dana. "She even has her own mermaid tail."

By contrast, walkers at the Lewes leg enjoyed a sunny day at Cape Henlopen State Park on April 16. To mark the anniversary in Lewes, 511 of almost 800 walkers formed the world's largest human puzzle piece. When this newsletter went to the printer, organizers were waiting for official notification from *The Guinness Book of World Records*.



This year's walk grand marshal in Lewes was 14-year-old Blaine Clark. The Mariner Middle School student is the son of Lucinda K. Bunting, DMD. Captain of Team Diamond State Dentistry, Bunting also celebrated as a 10-year participant in the event.

As a statewide autism agency, Autism Delaware helps people and families affected by autism by addressing the range of services they need to live full lives as valued members of their communities. "Families affected by autism need a wide range of services," explains Autism Delaware executive director Teresa Avery. "To meet the growing need, we need to continue to grow. We're proud to say we made our fundraising goal of \$200,000."

In addition to the walkers' fundraising effort, the following individuals and businesses contributed as 2016 Walk for Autism sponsors:

Presenting sponsor—Horizon Services

Champion sponsors—Swift Pools and the Brandywine Center for Autism

Partner sponsors—Bath Fitter®, C-Ink, Highmark Delaware, TR&P, Nuclear Electric Insurance Limited, UnitedHealthcare, and International FG Solutions™

Media sponsors—iHeart-Media, Fox Sports, 1290AM Wilmington, Mix 92.9, Newsradio 1410 WDOV, and 94.7 WDSB

Advocate sponsors—Beebe Healthcare; CSC; John F. Kleinstuber & Associates, Inc.; Sharp Energy; Swiatowicz Dental Associates; Carman Fiat; Dogfish Head Craft Brewed Ales; and ANYTIME FITNESS



Many thanks to everyone for a successful Walk for Autism season!

INSIDE Autism™ Delaware

Gathering of friends at 2016 Drive for Autism

Autism Delaware co-founder Artie Kempner greeted his “gathering of friends” under the clear morning sky of May 12. In front of the Brantwyn Estate (across the street from the DuPont Country Club), 230 sports celebrities and Autism Delaware sponsors and their teammates arrived to play in the 15th Annual Drive for Autism Celebrity-Am Golf Outing. Fundraising for the event is still coming in, and Autism Delaware expects to break the goal of \$400,000.



“Many of the returning sports celebrities have personal connections to autism,” notes Kempner, “but even those who don’t have made an every-year event of our golf outing.”

At top left, Kempner welcomes Olympic gold-medal swimmer Theresa Andrews.



At left, Autism Delaware associate director Brian Hall jokes with NASCAR driver Regan Smith.

Driving his own golf cart is legendary stock car driver Darrell Waltrip, winner of 84 NASCAR Cup Series races and three-time champ, who now serves as lead analyst for NASCAR on FOX.



Below center, four-time Sprint Cup champion Jeff Gordon poses for photos with golfers



before turning his attention to fundraising at the Drive for Autism’s live auction.

And at right, Danica Patrick enjoys the day on the golf course before returning to Dover International Speedway. Patrick drove the No. 10 Nature’s Bakery/Autism Delaware Chevrolet at the AAA 400 Drive for Autism. This NASCAR Sprint Cup Series race took place May 15.



Green flag from Smithfield Foods

Back in April, Smithfield Foods was announced as the presenting sponsor of the 2016 Drive for Autism Celebrity-Am Golf Outing with the unveiling of the new No. 43 Ford Fusion atop the 46-foot Monster Monument at Victory Plaza at Dover International Speedway. The event also kicked off festivities for the AAA 400 Drive for Autism at Dover.



Among the guests at the unveiling were (above, left to right) Artie Kempner, driver of the No. 43 Richard Petty Motorsports Ford Fusion Aric Almirola, The King of NASCAR Richard Petty, Smithfield Foods vice president of corporate marketing Bob Weber, and president and chief executive officer of Dover International Speedway Mike Tatoian.

“We learned of the event through Aric,” notes Smithfield Foods VP Bob Weber, “and we needed to be involved. Autism is very personal to all of us at Smithfield, as the crew chief of our No. 43 and our executive vice president, both are parents of children with autism.

“Autism Delaware is doing outstanding work,” adds Weber, “and we trust that, through our support, so much more can be accomplished.”

Golf photos at left by Rocco Bisciegli

Where the money goes

When you fundraise for Autism Delaware, the money supports the range of programs and services needed by families and individuals with autism across their lifespans.

In addition to the programs listed on this page, Autism Delaware also offers clinical services for children, adult employment services, advocacy at both the state and local levels, and autism awareness.

For details, visit autismdelaware.org.

July

2—Sensory friendly movie: *The BFG* or *Tarzan*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

13, 20, 27—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. **Register:** Karen.Tuohy@redclay.k12.de.us.

8—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30PM. **Register:** Heidi Mizell at (302) 224-6020.

12—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00AM. **R.S.V.P.:** Heidi Mizell at (302) 224-6020.

14—Grandparents support group. Autism Delaware Lewes office. 9:00–10:00AM. **R.S.V.P.:** Dafne Carnright or Gail Hecky at (302) 644-3410.

16—Sensory friendly movie: TBD. Westtown Movies. 150 Commerce Dr. Middletown. 10:00AM.

Programs

July (continued)

16—Family night at the Blue Rocks. Frawley Stadium. Wilmington. Picnic starts at 6:15PM. Game starts at 7:05PM. **Register:** <https://interland3.donorperfect.net/weblink/weblink.aspx?name=E202753&id=20>.

23—Sensory friendly movie: *Secret Life of Pets* or *Ice Age: Collision Course*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

August

3, 10, 17, 24, 31—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. **Register:** Karen.Tuohy@redclay.k12.de.us.

11—Grandparents support group. Autism Delaware Lewes office. 9:00–10:00AM. **R.S.V.P.:** Dafne Carnright or Gail Hecky at (302) 644-3410.

13—Sensory friendly movie: *Pete's Dragon*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

15—Grandparents support group. Autism Delaware Newark office. 6:30PM. **Register:** Heidi Mizell at (302) 224-6020.

16—Bounce night. Shell We Bounce. 20699 Coastal Hwy. Rehoboth Beach. 5:00–7:00PM. **Register:** Gail Hecky at (302) 644-3410.

20—Sensory friendly movie:

- TBD. Westtown Movies. 150 Commerce Dr. Middletown. 10:00AM.
- *Kubo and the Two Strings*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

28—Beach picnic. Cape Henlopen State Park. Lewes. 11:30AM–3:30PM. **Register:** Gail Hecky at (302) 644-3410.

The Starkey family at the 2015 beach picnic

September

7—Parent coffee hour. Hampton Inn. 117 Sandhill Dr. Middletown. 9:30AM. **R.S.V.P.:** Heidi Mizell at (302) 224-6020.

7, 14, 21, 28—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. **Register:** Karen.Tuohy@redclay.k12.de.us.

9—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30PM. **Register:** Heidi Mizell at (302) 224-6020.

10—Sensory friendly roller skating. Christiana Skating Center. 801 Christiana Rd. Newark. 5:15–7:15PM.

12 or 14; 19 or 21; 26 or 28—Junior golf. The Rookery South Golf Course. Milton. Choose one of two days per week, one of two times per day: 4:30 or 5:15PM. **Register:** Gail Hecky at (302) 644-3410.

13, 20, 27—Lego club. Autism Delaware Newark office. 6:30–7:30PM. **Register:** Heidi Mizell at (302) 224-6020.

15—Speaker series: Val Budischak, Epilepsy Foundation. Autism Delaware Newark office. 6:30PM. **Register:** Heidi Mizell at (302) 224-6020.

17—Sensory friendly movie: TBD. Westtown Movies. 150 Commerce Dr. Middletown. 10:00AM.

24—Sensory friendly movie: *Storks*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.



PARENT PARENT

Teaching your child's classroom about autism Continued from page 1

Deciding how much information to share

When my older, neurotypical son Frankie was in the fourth grade, begins parent Jen Nardo, he wrote a book report about a child living with autism. During Frankie's oral report, he talked about his younger brother Jake and some of the challenges our family faced at the time. Another boy in the class told Frankie to "get his brother a brain." The comment cut Frankie to the bone.

Sadly, no teacher took it seriously. But I wanted to make sure that this never happened again—to my son or any other child. As a parent, I didn't have a choice about whether or not to share my story. It was time, notes Nardo.

After approaching the headmaster of Frankie's school, we made a plan to turn this ignorance into a teachable moment. I invited Special Olympics Delaware to come talk. Frankie spoke as well, talking about the great things that happened to him because of his brother Jake: meeting a famous NFL quarterback, receiving a special pass to Walt Disney World. And I spoke about all that makes Jake just like any other kid: his love of pizza, French fries, the beach, and so on.

I also covered the basics of Jake's diagnoses, which include fragile X syndrome, attention deficit disorder, and generalized anxiety disorder as well as autism. The hard part was keeping the information at an appropriate level for fourth through eighth graders, but I found that photos of Jake and a short video fit the bill.

I have always had the attitude that sharing stories and information about Jake was the better approach. If I convey my comfort with Jake's challenges, anyone meeting Jake would be comfortable, too.

I also encouraged questions and told parents to tell their kids to "Ask away," adds Nardo. I would rather have someone ask me about a topic that feels awkward than to have an awkward silence or a raised eyebrow.

For your child with autism, there are many ways to approach the subject in his or her class—as well as in a sibling's class. Here's one I have tried and the kids liked: Hand out crackers, and ask the class to chew only a little and try to speak. When the students can't make anyone understand them, they get an idea as to how it feels for those who can't speak clearly or maybe at all.

Another suggestion I have is reading a book about autism spectrum disorder. A younger class would appreciate *The Autism Acceptance Book*, by Ellen Sabin, or *All About My Brother*, by Sarah Peralta.

A class might also enjoy coloring books with similar messages, such as *My Friend with Autism: A Coloring Book for Peers and Siblings*, by Beverly Bishop (author) and Craig Bishop (illustrator). It can be bought online at <http://www.amazon.com/My-Friend-Autism-Coloring-Siblings/dp/1885477899>.

In the end, sums up Nardo, I believe that the more we share our families' stories and show how wonderful our children who live with autism really are, the more we will find compassion and acceptance in the world.



Jake Nardo

From the desk of Autism Delaware's resource coordinator

How you would benefit from Smart911

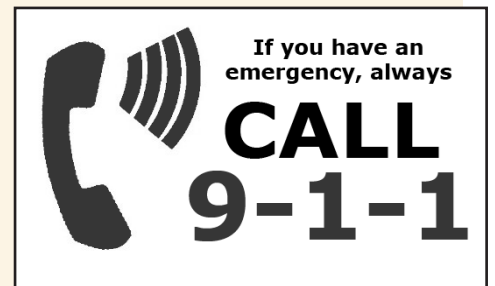
Imagine that something happened to you while walking or driving with your child who wanders—and 9-1-1 is called. Wouldn't you want emergency responders to know that your child on the spectrum should be with you but may have wandered off?

Or what if your child calls 9-1-1 but is too panicked or unable to say what's wrong? The information received by the 9-1-1 call center is limited to the type of phone being used.

Smart911 is a free, private, and secure nationwide service that provides the details that a 9-1-1 operator may need. Once you register and create your Safety Profile, it "will only be displayed to a 9-1-1 call taker if you place a 9-1-1 call from a phone confirmed

with your Smart911 account, and the 9-1-1 center receiving your call participates in the Smart911 program. You are in full control of the information you enter and the phone numbers you choose to associate with your Safety Profile" (<https://safety.smart911.com/how-it-works/faq>).

For more information, visit <https://safety.smart911.com/how-it-works/faq>.



—Heidi Mizell

Providing an environment for success

Do you want to play?

Sun contributor Candace Shetzler, MS, OTR/L, is an occupational therapist, parent, child advocate, and director of EBS Children's Therapy Center of Delaware in Lewes and at Cape Integrated Wellness.

What does it mean to play? It means different things to different people and certainly something different to a child. In the world of occupational therapy, play is a child's job—work that requires focus, engagement, skills, attention, motivation, frustration, rewards, feedback, pleasure, and uneasy moments. This is a powerful statement because it mirrors most adults in their occupations. And like an adult with a new job, child's play doesn't always look pretty; it certainly isn't perfect. It's a process, an evolution that involves growing pains and requires support, the freedom to make mistakes, non-judgmental responses, and a great environment for learning.

Begin by taking some pressure off you and your child: Let others know about your child's level or what he or she is currently working on. For example, "We are working on playing next to friends right now, so we will see how today goes."

Next, consider the elements needed for successful play just as you would for any skill that is being learned or explored:

- environment or context
- space
- people
- environmental stimulation, such as noise, the number of people and toys, and place options

Other elements that matter are your child's age and the other children's ages, your child's developmental ability and level, level of engagement and joint attention, communication abilities, picture support availability or partners who can sign or use gestures, and the number of play partners involved.

Note: When planning a play interaction or watching one spontaneously unfold, adjust your expectations. A child has to filter and integrate a lot of input. First, observe if the child is able to self-regulate when approaching the environment, situation, and people.

As a guide for continuing, also observe these indicators:

- Is the child able to remain relatively calm or experience mild excitement or hesitation?
- What does the child sound like? Is he or she quiet, humming, squealing, laughing?
- How does the child look? What are his or her facial expressions, and is he or she flushed or reddening?
- What is the child's body doing? Gearing up (running, jumping, or bouncing) or shutting down (clinging, hiding, or cowering).



Note: We never want to force an interaction or play engagement. We start by modeling the

behavior we hope for, such as greeting another child, making eye contact, giving a friendly smile, or holding up something to show a peer. Then, proceed with free exploration or the guided exploration of one to three items that the child might find interesting or be motivated to engage with.

Other points to consider:

- Upon your child's first approach to the play setting, allow for free play and open exploration without expectation. We all like to get the lay of the land on our own timetable.
- If planning a meeting, meet on comfortable territory for everyone concerned.
- Use song to foster familiarity, engagement, and proximity.
- Get on the floor, and play with your child (unless you are trying to fade out for greater independence).
- Use items that foster a back-and-forth exchange, such as balls.
- Use items that motivate, not cause your child to obsess.
- Chase is a game; it's okay!
- Use play around gross-motor skills to your advantage—even if only taking turns to roll down a hill or jump over an obstacle.
- Model and imitate for your child and others, and encourage your child to imitate in return.
- Think about social opportunities that are fun for the children involved, such as snacks and meals, outdoor time, and a trip to the playground. And note: Are these times happy for your child or stressful?
- Praise your child and the other children. And be specific! We all like to know when we are doing a good job.
- Sharing is not required! Depending on what developmental stage your child is at, simply sharing space or eye contact can be a victory.
- Follow your child's lead, and relax. Remember, we all want to enjoy our "jobs."

Supporting play is a balancing act for the most skilled therapists. For parents, it's an even greater challenge because we must maintain our own balance during the process. But by taking the pressure off and relaxing, you can help your child through the growing pains while offering support, the freedom to make mistakes, nonjudgmental responses, and a great environment for learning.

Being a team player

Observing your child in the classroom

This reprint has been made possible with permission from the author, Katie Cooper, and CT FEAT Inc. (2010).

Short for Connecticut Families for Effective Autism Treatment, CT FEAT is a nonprofit formed by parents to provide information, support, and networking opportunities for the families of children with autism spectrum disorder (ASD).

For more information, visit <http://www.ctfeat.org/index.htm>.

Whenever a parent expresses concern about [his or her] child's lack of progress at school or home, my first piece of advice is to get into the classroom to see what is happening. Over the 13 years my son has been in school, I have learned a tremendous amount by observing him there.

Why do I go into the school? I need to see what my son is and isn't doing there. Like many children on the autism spectrum, he has difficulty generalizing skills to new people, new areas and new materials.

Sometimes he does things in class that I didn't know he was capable of. Sometimes he is not doing things there that he is capable of doing at home. By observing him at school, I can help him generalize skills across all settings: in the school, home and community.

Requesting permission to observe

How do parents get permission to visit their child's classroom? Most schools have a written policy about parent observations/visitations. The policy usually includes notifying the staff ahead of time, signing in and out of the school, and picking up some type of badge to indicate you are a visitor. Sometimes they may want another staff person to accompany you throughout your stay.

Before requesting permission to observe my son, I determine just why I need to visit. I look over the individualized education program (IEP) to see which objectives seem to be mastered at home and which have not. Then I ask myself: About which skills am I most concerned? Which teaching approaches would I like to see demonstrated?

I usually deal directly with my son's teacher in setting up the time. I might say "I'd like to come in and observe him doing X. When would be a good time?" or "I'd like to observe him during story time. Would Monday or Wednesday be better for you?" Note that both ways you're not asking for permission; you are asking [the teacher] when a good time is.

I also respect the teacher's answer. If she tells me that some of her staff have asked for a day off so she'll be shorthanded or will have substitute paraprofessionals in the room, I choose another day. I want to see my son on a typical day.

A teacher's perspective

I taught school for many years and I know that there are parents who don't know how to behave appropriately in the classroom. But in my experience, they are the exception and not the rule.

I always make an effort to demonstrate, by my overall behavior, that I am not interested in critiquing the staff or in observing anyone's child but my own. I'm there purely as a member of the pupil placement team (PPT) with the goal of making a constructive contribution to my son's educational program.

If a teacher or a school were to refuse me permission to observe, it would be a HUGE red flag for me. Of course, a parent should cooperate with the overall schedule and routine of the school and abide by all reasonable suggestions as to when to attend and where to place yourself in the room.

The key to being welcomed into a school is to have respect for the staff and to conduct yourself appropriately. If you word your request politely and make your legitimate intentions plain, no school or teacher should refuse you. If they do, ask to see the written policy about school observations or visitations.

If the teacher tells you that your visit will disturb the rest of the class, reassure her that you won't be interrupting. Find a place to sit in the room where you can see [or] hear and then just sit quietly.

Some parents report that teachers have tried to discourage them by claiming that the child would be upset and distracted by their presence. My son's first therapist from CREC [Capitol Region Education Council in Connecticut] told me, "If it bothers him to see you in the room, then you need to come in more often. He should be able to look up, say 'hi mom,' and go back to work [or] play."

Other parents have found it worthwhile to observe their children by volunteering in the classroom. Teachers are often grateful to have extra hands preparing class materials and otherwise helping out as needed. Working under the teacher's direction, parent volunteers help all of the children in the class and not just their own.

How to observe

In order to see and hear what is happening, I have not always needed to be physically in the classroom. Some schools will have a remote camera and microphone set up in the classroom that allow you to watch and listen from another room. Others have observation rooms where you can see and hear what your child is doing.

But sometimes that may not be adequate. For example, my son's current classroom has an observation room with a two-way mirror. But I am not able to see the materials well enough to really understand what he is or isn't doing. Therefore I go in the classroom and observe there.

Continued on next page, column 1

Observing Continued from page 10

Four easy rules for successful classroom observation

1. Don't interrupt the teacher or the lesson.

If I see something I don't understand or would do differently, I make a note to talk to the teacher at some more appropriate time. Many teachers are concerned that you're really in the room to judge them and will get flustered if you interrupt what they are doing. That's not fair to the teacher and it's especially not fair to the children.

2. Observe only your own child, not the other children in the room.

I'm not looking around to see what skills the other children are working on or to determine what services they get. I wouldn't want a stranger observing my son for such improper reasons so I won't do it to others. I respect the privacy and confidentiality of every child in the class.

3. Let the teacher know ahead of time the skills you'd like to see.

Often, time is limited, so if there's a certain skill I want to see my child perform, I let the teacher know. Sometimes my son will do things for the teacher that he won't do for me. Seeing it done, I know I can make him accountable for bringing those skills home. Likewise, my son may have skills at home that he's not demonstrating at school. When I share that fact at the monthly meeting, the school staff [members] can then increase their expectations of him at school.

4. Take notes about what you are seeing.

I have one notebook dedicated solely to school observations. This helps me share what I've learned with the teacher and my husband. Otherwise it can be hard to remember the important details until the next monthly meeting or opportunity to speak with the teacher.

A winning team

A parent has the right to be in the classroom. As part of the PPT team you need firsthand knowledge of what your child is and isn't doing there. If you prepare and behave appropriately, the experience will be pleasant and constructive for all concerned.

Introducing your child to the classroom Continued from page 1

Every situation is different, so each family and school must decide the best time to introduce the subject of autism and a child with autism to classmates.

Grade level

All children are the right age to learn about inclusion and respect, notes Gilden, but the way you present the information will vary between grades.

For younger classes, you may consider reading a picture book, bringing in an autism-themed snack (like puzzle piece cookies), or doing an arts and crafts activity with the children. The main message can include

- kids with autism have brains that work a little differently.
- we all have things we're good at and things we need help with.
- how to be a good friend to someone with autism.

For older students, information can also be presented in a variety of ways.

Consider a movie, group project, word searches and crosswords, a

PowerPoint presentation, or a service project. The main message can include

- kids with autism are just different, not less.
- everyone can contribute to the world in his or her own way.
- helping people with disabilities benefits everyone.

Many parents worry about how their children on the spectrum will be received by the rest of the world as well as by regular-education students. As a parent, sums up Gilden, you can relieve some of these fears by speaking directly to your child's classmates. Not only will the information help minimize the classmates' fears and negative attitudes, but it will also foster helpful, loving friends at an early age. And by creating an accepting environment in the classroom, families help shape how the world sees their children.

For more information

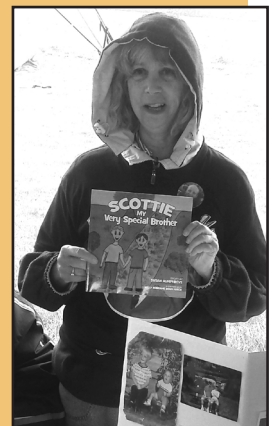
- **School Community Tool Kit, by Autism Speaks**
<https://www.autismspeaks.org/family-services/tool-kits/school-community-tool-kit>
- **Kids Booklet on Autism with Tips for Parents and Teachers, by Autism New Jersey**
<http://www.autismnj.org/document.doc?id=157>
- **Educating Children about Autism in an Inclusive Classroom**
www.gov.pe.ca/photos/original/ed_autisminc.pdf
- **Children's books**
 - www.bellaonline.com/subjects/9393.asp
 - www.autism-resources.com/books-children.html

Book brings donations to Autism Delaware

Scottie, My Very Special Brother portrays events that actually happened to Susan Humphreys' sons, Brad and Scottie. Written in loving memory of Scottie, who had autism, Humphreys hopes this first-time effort "will help children understand some of the common behaviors of autism" (<http://www.scottiemyveryspecialbrother.com>). This children's book is also a first-time effort for illustrator Kelly Reibsame Denelsbeck.

Each edition costs \$6.00 and can be ordered at scottiemyveryspecialbrother.com.

For every book sold, \$1.00 will be donated to Autism Delaware!





924 Old Harmony Rd.
Suite 201
Newark DE 19713

Nonprofit Organization
U.S. Postage
PAID
Permit #317
Newark DE

Return service requested



Helping People and Families Affected by Autism

***Where can you go to have lots of fun
while supporting families living with autism?***



You have a choice!

**The Nassau Valley Vineyards in Lewes on Friday, Sept. 16—
the 2016 Blue Jean Ball**

**The World Café Live at The Queen
in Wilmington on Friday, Nov. 4—
the 18th Annual Auction for Autism**



**Both offer food and fun entertainment—and both will provide
instant-access bidding on one-of-a-kind goods and services.**

**All proceeds benefit Autism Delaware's range of programs and
services needed across the state.**

For more information, visit

autismdelaware.org