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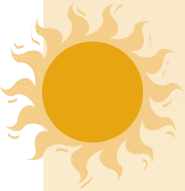
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Our mission

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



The Sun

Newsletter

July–September 2015

A conversation with parents

The benefit of hindsight

If only I knew then what I know now! How many times have you uttered these words? Seeing a situation with the benefit of hindsight, you would have handled it much differently. Your child's first day of school may be one of these situations. A lot of questions pop up as both you and your child face a major transition: *How will my child adjust to being in a different environment? Will my child have teachers who understand autism—and understand my child? How will the other kids in the class treat my child? How do I get the services my child needs?*

Looking back on these questions and a myriad more concerning the transition to school, five Delaware parents share their experiences and advice here. They hope you can benefit from their hard-earned hindsight.

“My son started school in 2004,” says Kate Stomieroski. Her son Jack was diagnosed with high-functioning autism four months before starting preschool at the John S. Charlton School in Dover. “I learned quickly that, if you don’t advocate for your child, no one else will.”

“I wish I had known then about Wrightslaw,” adds Stomieroski. “This resource would have prepared me for the IEP [individualized education program] meetings and issues that many of us faced in those early days.”

“I had valid concerns, too,” says Stacey O’Rourke about meeting her daughter’s IEP team, “but in the early days, I did not communicate effectively, because I was so emotional. I did not always follow my gut, and I was right on some things. I also talked to other par-

ents who gave me good advice, but I didn’t listen—and they were right.

“I also found that a new school team may use a different strategy than a prior team,” continues O’Rourke, “and then, I’d get confused as to what I am supposed to do to carry over instructions at home. Observing a new team and using a high level of communication can help address this.

“I have since learned how to talk with the team and how to work with the team’s style. A little diplomacy is called for. I talk about only the facts and ask for help in understanding an issue. I think, if you say you are not judging but want to learn from the team, you find out more about what’s going on at school. And I have learned how to find a balance between getting more services and understanding realistic expectations.

“For questions,” adds O’Rourke, “parents should reach out to organizations, such as the Parent Information Center,

Wrightslaw.com focuses on special education law and advocacy and offers resources concerning special education.

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The Sun

A publication of Autism Delaware™

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Growing education services with the need

A diagnosis of autism in a family often brings shock and pain and grief. Through the haze, most people begin focusing on school: *How will my child learn? Is there a place that can help him? Will she ever be successful?* The early years of entering into the world of autism become consumed by worrying about, learning about, and getting involved with school. This issue of *The Sun* has a lot of great advice about what to expect and how to navigate the school system. I want to explain a little about the work that we are doing to improve education services for all children with autism in our state.

Here in Delaware, we have a unique history of educating children with autism. The Delaware Autism Program (DAP) was established in 1979 by a pioneering group of parents who envisioned a level of evidence-based practice and excellence that was rare at the time. Since the DAP was serving a small number of students in those early years, it made sense to consolidate them together in one district per county. This consolidation made it possible to pool the expertise and to fully support the staff working in this very challenging environment. DAP was a model program that enticed people to move here and changed the lives of many, many students and families over the years.

I've talked in this column before, however, about the critical need at this point to change and update the model. Over the last 15–20 years, the rapidly growing number of children with autism has strained the DAP's

resources almost to the breaking point. In addition, more and more students are being served in their home districts, often without good training and programmatic oversight for the staff. We are long past the point where we can tolerate a system where some students are being served in a DAP "approved" program while many others are not.

Last year, Autism Delaware worked with Senator Margaret Rose Henry (D-Dist.2) to push for legislation that established the Delaware General Assembly Autism Educational Task Force (For a review, see "On the autism educational task force" in the April–June 2015 edition of *The Sun*). When this legislation passed in June 2014, we joined forces with many other interested parties, rolled up our sleeves, and got to work. It was good timing that the Center for Disabilities Studies at the University of Delaware had recently finished leading a project creating the *Blueprint for Collective Action* for autism. The work that went into creating this document, including participation by Autism Delaware staff and input from professionals and families around the state, gave us a strong basis and direction for our work. Our task force was charged with figuring out how to



Marcy Kempner
President

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A service of Autism Delaware



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Growing education Cont'd from p. 2

create and organize the training and the technical assistance teams called for in the blueprint and, more importantly, to figure out how to fund them.

That is a brief synopsis of the problem and the process. As of this newsletter's printing, I am proud to say that we have a creative and collaborative plan to accomplish our goals. We are working with Sen. Henry and Representative Earl G. Jaques (D-Dist. 27) to introduce two pieces of legislation:

1. Amend Delaware law pertaining to the education of students with autism to create training and technical assistance teams to work with staff in every district throughout the state.
2. Establish the Delaware Network for Excellence in Autism to administer training and technical assistance not only for school staff, but also for professionals working with people with autism across various systems.

We are optimistic that we can get both of these interrelated pieces of legislation passed during this legislative session, but we know that it will take a lot of work and many, many voices advocating to make it happen. If it doesn't happen this session, we will not give up! We will continue to push for these changes until we've improved systems from education to health care to social services for all of our loved ones with autism.

Please stay tuned, stay connected, and make sure that your voice is heard when we ask for help in advocating for these important initiatives. If you have any questions or want to get involved, please contact Autism Delaware's policy and community outreach director, Alex Eldreth. He can be reached at Alex.Eldreth@delautism.org or at (302) 224-6020, ext. 204.

In the meantime, good luck with school this fall! Stay involved and communicate every day with your child's school team. Staying connected to school as much as possible will help you through the tough times and get you on the road to a brighter, more hopeful future. And together, we can create a brighter, more hopeful future for all of us.

Autism advocates come out for Smart Cookie Day at Leg Hall

Every April, Autism Delaware sets aside one day on which to help autism advocates speak to their state legislators. Called Smart Cookie Day, this year's meet and greet took place on the same day as World Autism Awareness Day: April 2.

The advocates' goal was to ask for legislation that helps meet the needs of individuals with autism and their families while sharing their personal stories and hand-delivering fresh-baked cookies—generously donated by a Wilmington bakery.

The day began with a news conference on the back steps of Delaware Legislative Hall in Dover. Autism Delaware executive director Teresa Avery, MBA, opened with the most up-to-date information on autism and included what Autism Delaware is doing to meet the growing need statewide.

"The need grows with the number of people who are affected by autism," says Avery. "For Delaware's 2014–15 school year, for example, 1,512 students have an educational classification of autism. In 1991, only 152 did. This is an 895-percent increase over 23 years. At Autism Delaware, we're working to help meet the need, but we're seeing a lot more need."

Focused on the legislative issues during the news conference were Del. Sen. Margaret Rose Henry (D-Dist. 2), Del. Rep. Earl G. Jaques (D-Dist. 27), Del. Rep. Mike Ramone (R-Dist. 21), and Del. Rep. Gerald Brady (D-Dist. 4). Center for Disabilities Studies program coordinator Annalisa Ekbladh gave an update of the Delaware General Assembly Autism Educational Task Force.

Approximately 30 autism advocates were then led inside to meet with their legislators. A tribute to World Autism Awareness Day was also read on both the Senate and House floors.

Smart Cookie Day ended with a meet and greet at Frazier's Restaurant on the Waterfront in Dover.



Top: Del. Sen. Margaret Rose Henry and Del. Rep. Earl G. Jaques

Above: Sen. Henry met with several advocates, including Marcy and Artie Kempner with their son Ethan.

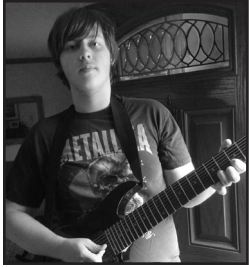
Below: Following his appearance at the United Nations for World Autism Awareness Day, Gov. Jack Markell signed a proclamation naming April as Autism Awareness Month in Delaware and then made time for the autism advocates.



PARENT PARENT

Written by parents
for parents

Preparing the teacher for a higher-functioning child



William Provine

Asperger's syndrome, high-functioning autism, mild autism, autism spectrum disorder: Whatever we call it, it places our kids in a class by themselves—or in classrooms by themselves: the lone autism representative in a field of neurotypical (NT) peers.

On my son Will's first day of school, I often feel like I'm abandoning my beloved sheep among a pack of wolves. So, I've learned to enlist and empower his teachers to be his shepherds in my absence.

During the very first week, I talk to every single teacher. That's Every. Single. Teacher. Period. I include the art, gym, and music teachers plus any adult who has supervisory time with my son.

To start, I meet the guidance counselor in late summer to ask for advice on the best way to connect with Will's new teachers. I use the guidance counselor's mojo to win the attention of reluctant teachers. After four years at Will's current school, the counselor now gathers the teachers together for me for a group debriefing!

I prepare carefully for these meetings and use a simple analogy to explain Will's autism: *Computers have different operating systems: Microsoft created a DOS (disk operating system). Apple uses an iOS system (for Internet or individual). Both operating systems are extraordinary, and with software, they can talk to each other.*

Like computers, human brains have differences. Most of us run on a "TOS" (typical operating system), and Will has an "AOS" (autism operating system). These systems work differ-

ently, but we can still communicate if we learn to interpret what we say to each other. The effort to understand is our software.

During the teachers meeting, I want Will's teachers predisposed to seeing him as an asset, not a burden. So, I begin with something positive: *Will is an eager learner and tests well in math and science. The classroom is also Will's wheelhouse. Here, he can find order, a leader, a routine.*

Because of Will's grades and polite behavior, he is ineligible for formal educational assistance. As a result, Will has no IEP (individualized education program), 504 plan, or teacher's aides, but because of autism, Will needs supports to survive the changing circumstances of the school day. At this point in the teachers meeting, I offer a brief list of the deficits in Will's executive function, sensory, social, and motor function processes as well as his anxieties and quirks. I also suggest a potential support for each challenge and welcome the teachers to imagine alternative solutions.

This conversation is the heart of each meeting. Most teachers become sensitive to Will's challenges as well as his potential, and they begin to feel invested in his success. Importantly, this meeting also sets up my partnership with the teachers. I routinely check in with Will's homeroom teacher and advisor either by email or in person. And I give my contact information to all the teachers so they can loop me into discussions about any academic, emotional, or social fail.

Some years have run smoothly; others have been more volatile. But overall, this initial conversation each fall, in which I am frank, detailed, and unapologetic with Will's teachers, has ensured that my son always has at least one adult champion on campus—no matter what happens during the school year.

—Annie Woolard-Provine

Must-read:

Smart-Shaming: Sorry But Your Child Is Too Bright to Qualify for Help, by Daniel B. Peters, PhD.

Find it at http://www.huffingtonpost.com/daniel-b-peters-phd/sorry-but-your-child-is-t_b_7223364.html.

Considerations throughout the school years

Hailing the importance of good teachers, Temple Grandin, Ph.D., covers the education of children with autism spectrum disorder (ASD)—as well as some of her personal educational experiences—in her article entitled *Teaching ASD Children and Adults*. Published on the Autism Research Institute website, the article also lists possible affects that may need to be addressed in a classroom as well as their interventions.

Here, Autism Delaware borrows a number of Grandin's listed affects and interventions because of their need to be consid-

ered throughout any child's school years. "Whether or not your child has an IEP [individualized education program] or 504 plan," says Autism Delaware resource coordinator Heidi Mizell, "and whether your child attends school in a special-ed or a general-education classroom, you should consider these interventions to

Continued at the bottom of p. 5

Temple Grandin was named by *Time* magazine as one of the 100 most influential people in 2010 (<http://grandin.com/temple.html>).

A former teacher with the Delaware Autism Program, Sun contributor Debra Lewkowitz, M.Ed., is currently an educational diagnostician at Thurgood Marshall Elementary School in Newark.

Going back to school

Going back to school in the Delaware public school system can be challenging for some children with autism spectrum disorder (ASD). But with a few simple strategies, their parents and caregivers can ease the return.

Establish a routine

Nearly all children with ASD crave routine. They want to know what will happen and when—and they want to know these things before they happen.

If your child’s school year is about to start, establish a routine now. For example, set the time to leave for school and the method for getting

there as well as the time to do homework and bedtime. And make sure your child understands each step in this routine—in advance.

Review classroom rules

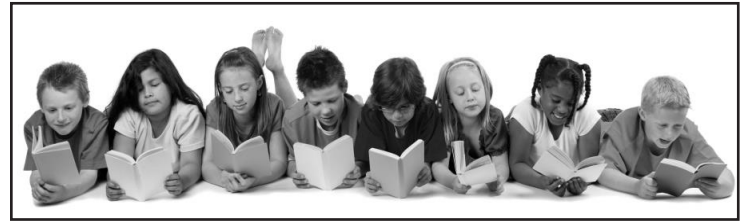
Spending some time now on your child’s classroom structure and schedule can reduce problems later, so review the rules of your child’s classroom and school. And remind your child of the expectations for the school year, such as how to treat classmates, complete schoolwork, and follow a schedule. Also, remind your child about the reward system, if you have one in place, and let your child know where the rules are posted and who to ask questions about the rules.

Introduce changes

Introducing children with ASD to changes in their routines helps reduce the stress that comes with new situations, so clearly explain to your child any changes that have taken place while your child was out of school. Examples include a new teacher, a new schedule, or even room arrangements that may be challenging to your child. And be sure to include how the change will affect your child.

Include your child in the process

Depending on your child’s age, allow him or her to help create the routine. Let your child have input into what time to do homework, where to do homework, and when to go to



bed. The more input your child has on these issues, the more comfortable and cooperative your child will be.

Review and reinforce the rules—often

Children with ASD may need extra reminders if they have a hard time remembering specific rules, so be sure to set aside time during your child’s first few days back in school to review the rules repeatedly. Consider a written or picture format, whichever your child responds to better.

When your child does a good job—completing work, following a schedule, or acting appropriately—be sure to reinforce the behavior. To do this, clearly indicate what your child did correctly so he or she can continue the behavior. For example, “James, I like the way you remembered to start your homework when you got home from school.”

Keep everyone informed

As the parent or caregiver of a child with ASD, you want everyone at school to understand who your child is and to know what your child’s special needs are. Ensure open lines of communication by speaking personally with your child’s teachers, aides, guidance counselor, and the school principal.

If possible, contact your child’s teacher well in advance of the first day of school, and explain that you want to be kept informed of your child’s progress in a timely manner. Include whether you prefer emails or in-person visits and how often. By setting up this line of communication at the very beginning of the school year, you can ensure a steady stream of information about your child’s education and growth as a student in the Delaware public school system.

Considerations throughout the school years Continued from p. 4



help you plan for the next school year. They will help you clarify your child’s needs throughout his or her education.”

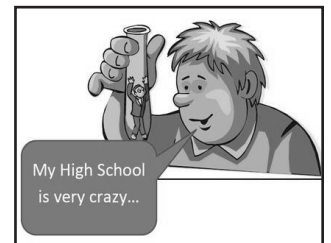
- If your child thinks visually, nouns are easier to learn than verbs, adjectives, or adverbs. To explain the meaning of these parts

of speech, each word needs to be demonstrated.

- If your child has echolalia (an involuntary repetition of words or phrases), flash cards and picture books can help a

child process words.

- If your child cannot remember sequences, long verbal instructions will lose him or her in the classroom. Written instructions are a better fit for your child.
- If your child has a gift for drawing, art, or computer programming, encourage these talents—and they will become skills for a future employee.



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INSIDE Autism[™] Delaware

Scholarship winners named

One of two \$1,000 winners of the 2015 Autism Delaware Adult with Autism Scholarship, Brandon Brown will continue his studies in the fall for the University of Delaware's career and life studies certificate (a post-secondary education program for students with intellectual disabilities) while continuing his education at Middletown High School.

The second 2015 winner, David Lee Cook, Jr., is a three-time recipient of the adult with autism scholarship. Cook is an actuarial science major at West Chester University and currently holds a grade point average of 3.953.

The winner of the \$1,000 Autism Delaware Para-to-Educator Stipend is Hockessin-resident Megan Cross. Having worked as a para-educator for several years, including two in the Delaware Autism Program (DAP) at the Brennen School, Cross graduated in May from the University of Delaware with a master's degree in education with a certificate in autism. Cross is now a special-education teacher at DAP.

Each winner of this year's Daniel and Lois Gray Memorial Scholarship will receive \$1,000 for her fall tuition at the University of Delaware. Each also intends to work in the autism field after completing her education:

- Madison Chase expects to earn her bachelor's degree in May 2016. The Long Branch

NJ native is majoring in cognitive science with a concentration in speech-language pathology and minoring in disabilities studies.

- Brianna Ciancaglini is majoring in psychology and minoring in exercise science and disabilities studies while maintaining active membership in the University of Delaware's Occupational Therapy Club and volunteering and fundraising for Autism Speaks.

- Mary Beth Elberfeld is working toward a Master of Education in Exceptional Children and Youth with certificates in autism and severe disabilities while maintaining active membership in Best Buddies.

- After transferring from James Madison University, Tess Hanley took a summer job as a paraprofessional at the Brennen School and now wants to focus her career on supporting children with autism spectrum disorder. Hanley is working toward a University of Delaware degree in cognitive science with a major in speech-language pathology.

- Valerie Hill is majoring in elementary education—special education and minoring in disabilities studies in the University of Delaware's College of Education and Human Development. Hill's goal is to earn a master's degree in autism and severe disabilities through UD's 4+1 master's program.

Did you know?

Autism Delaware provides year-round stipends to support attendance at autism workshops and conferences.

The \$250 stipend can be applied to related costs, such as registration fees, travel, hotel, and child care.

The stipend is paid once a recipient submits the receipts to Autism Delaware with a summary of his or her experience at the workshop.

Editor Carla Koss is available to help with your writing process if you need it.

To apply: In advance of the workshop or conference, submit a request to delautism@delautism.org. Be sure to include the workshop's name, date, and the anticipated cost.

Building a development team



David T. Woods

As the newest member of the Autism Delaware staff, David T. Woods experienced the fun and frenzy of the 2014 Auction for Autism—on his first day of work! Today, Woods is establishing himself as an integral part of a new development team that is gaining momentum. His goal is to help people and families affected by autism through planning, managing, and elevating various fundraising efforts.

"I hope we can encourage and inspire more individuals to support Autism Delaware's mission," says Woods. "It's important for people to understand we cannot support the hundreds of individuals and families that Autism Delaware serves without the generosity of the community. And we are extremely grateful for every gift—no matter the size."

Before joining the staff of Autism Delaware, Woods was an independent consultant for nonprofits in Delaware and greater Philadelphia, senior associate with Bloom Metz Consulting in Wilmington, president and chief executive officer of Social Venture Partners Delaware, and director of development and business manager at the Nativity Preparatory School of Wilmington.

For more information, call (302) 224-6020, ext. 206, or send an email to david.woods@delautism.org.

How can I contribute to Autism Delaware?

- Give directly at autismdelaware.org.
- Attend one of Autism Delaware's fundraising events.
- Organize your own third-party event.

More than 3,000 at Walk for Autism



Record-breaking attendance and weather extremes were the hallmarks of the 2015 Walk for Autism. The annual event raises funds that benefit Autism Delaware's range of programs and services, including family support, clinical services, advocacy, awareness, and the adult employment and community resources program known as POW&R (Productive Opportunities for Work & Recreation).



Photos by Leslie Sindlair

Sunscreen was in high demand at the Lewes leg of the statewide event, which took place April 18.

Autism Delaware board president Marcy Kempner introduced five-year-old Jacob Pantano as the grand marshal before he led more than 900 walkers at the official start. The route through Cape Henlopen State Park had been shortened by request to 2.2 miles. At the finish line, walkers gathered in the celebration fun zone where hands-on crafts were enjoyed, courtesy of Home Depot.



he led more than 900 walkers at the official start. The route through Cape Henlopen State Park had been shortened by request to 2.2 miles. At the finish line, walkers gathered in the celebration fun zone where hands-on crafts were enjoyed, courtesy of Home Depot.



Compared to the summer-like day in Lewes, the Wilmington leg on April 25 had volunteers looking for winter mittens during early sign-in! The temperature rose to a comfortable level by the time Autism Delaware development director David Woods introduced Melissa Chong as the grand marshal. The 26-year-old POW&R participant led more than 2,200 walkers at the start of the 5K. So many walkers filled the course that they extended for half a mile!

As in Lewes, walkers in Fox Point State Park gathered after the walk in the celebration fun zone.

The winner of the Lewes T-shirt contest was also announced: the gherkin green team, Pickle Power.

The winner of the Wilmington T-shirt contest was announced: Team Brenna.



Photos by Andrew Zeltt



Walk for Autism helps provide the income needed to make critical programs a reality. And this year, we met our goal: Walkers raised more than \$203,000! The top two fundraising teams are Team Ethan with \$19,990 and Team Graci with \$17,200. Plus, we raised more than \$16,000 from sponsors, such as Capital One and the Brandywine Center for Autism. As a parent with two children with autism, I want to thank you from the bottom of my heart.

—Autism Delaware events manager Deanna Principe



Photo by Andrew Zeltt

Volunteers make the difference

Thank you to more than 50 volunteers who worked the Lewes leg of the Walk for Autism—and to more than 70 who worked the Wilmington leg. You ensured that more of the raised funds go where they're needed.

Programs

July

1—Parent coffee hour. Hampton Inn. 117 Sandhill Dr. Middletown. 9:30 AM.

13—Parent coffee hour. Holiday Inn Express. 24058 Sussex Hwy. Seaford. 9:30 AM.

14—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.

23—Dads support group. Autism Delaware Lewes office. 7:00 PM. **Register:** Dafne Carnright at (302) 644-3410.



August

5—Parent coffee hour. Hampton Inn. 117 Sandhill Dr. Middletown. 9:30 AM.

11—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.

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

25—Parent coffee hour. Georgia House Restaurant. 18 South Walnut St. Milford. 9:00 AM.

September

2—Parent coffee hour. Hampton Inn. 117 Sandhill Dr. Middletown. 9:30 AM.

8—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.

23—Parent coffee hour. Holiday Inn Express. 1780 North Dupont Hwy. Dover. 9:00 AM.

24—Dads support group. Autism Delaware Lewes office. 7:00 PM. **Register:** Dafne Carnright at (302) 644-3410.

Last minute ideas Summer fun

July 16, August 6
Family bounce
Hopping Good Time
23 Cochran La., Camden
5:30–7:30 PM
Register: Gail Hecky at
(302) 644-3410

Teen/Tween game nights:
**July 10, August 14,
September 11**
Autism Delaware
Newark office
6:30–8:30 PM
Register: Heidi Mizell at
(302) 224-6020

**July 10, August 21,
September TBD**
Autism Delaware
Lewes office
6:00–7:45 PM
Register: Dafne Carnright
at (302) 644-3410

Every Wednesday
Family bowling night
Bowlerama, 3031 New
Castle Av., New Castle
5:30–7:00 PM
Register: Karen Tuohy at
(302) 633-3316

July 18
Family night picnic
at the Blue Rocks
Daniel S. Frawley Stadium
801 S. Madison St.,
Wilmington
Dinner at 6:15 PM
Game starts at 7:05 PM
Register: Kris Grant at
(302) 224-6020

Sensory friendly movies:
July 11, Minions
July 25, Pixels
August 15, Underdogs
**September 26, Hotel
Transylvania 2**

Sensory friendly movies (continued)

Carmike Cinemas in the
Dover Mall, 1365 North
Dupont Hwy., Dover
All at 10:00 AM

July 18, Minions
August 15, Underdogs
September 19, TBD
Westown Movies
150 Commerce Dr.,
Middletown
All at 10:00 AM

August 17–20
Summer day camp
Children's Beach House
1800 Bay Av., Lewes
9:00 AM–4:00 PM
Register: Dafne Carnright at
(302) 644-3410

August 23
Annual beach picnic
Cape Henlopen State Park
Main Beach Pavilion, Lewes
11:30 AM–3:30 PM
Register: Gail Hecky or Ann
Athas at (302) 644-3410

September 12
Skating party
Milford Skating Center
1 Park Av., Milford
5:00–7:00 PM

September
14 or 16, 21 or 23, 28 or 30
Junior golf program
The Rookery South
27052 Broadkill Rd., Milton
4:30 PM or 5:15 PM
Register: Gail Hecky or Dafne
Carnright at (302) 644-3410

September 19
Roller skating
Christiana Skating
801 Christiana Rd., Newark
5:15–7:15 PM

The legislative process takes on improvements in education



At the time this newsletter was printed, the Delaware General Assembly was discussing two bills that could improve education for children with

autism spectrum disorder (ASD) in the First State.

Senate Bill No. 92 (SB92) expands title 14 of the Delaware Code, which was enacted about 30 years ago to create the Delaware Autism Program (DAP). As a model of service delivery, DAP was considered ahead of its time, but with an 895-percent increase in the number of Delaware school children given an educational classification of autism—up in just the last 23 years—the program is unable to provide the level of services and support that it once did.

SB92 would “essentially expand available supports so that excellent, evidence-based training and technical assistance can be made available to all Delaware schools and the students within them,” writes SB92 sponsor Del. Senator Margaret Rose Henry (D-Dist. 2) in the bill’s summary.

As prime sponsor of SB92, Henry has gained the support of co-sponsors in the house as well as the senate: Sen. Cloutier,

Rep. Jaques, Sen. Townsend, Sen. Blevins, Sen. Ennis, Rep. Baumbach, Rep. Bolden, Rep. Gray, Rep. Hensley, Rep. Mitchell, Rep. Ramone, and Rep. B. Short.

The second bill being discussed in the general assembly is Senate Bill No. 93 (SB93), which establishes the Delaware Network for Excellence in Autism. The goal is to create a resource for training and technical assistance for state agencies and other organizations that provide support and services to individuals and families affected by ASD.

This bill also creates a committee on ASD with representatives from several agencies and would put into place the suggestions defined in 2013’s *Delaware Strategic Plan: Blueprint for Collective Action*. (For a copy of this publication, call the Center for Disabilities Studies at 302-831-6974.)

Like SB92, SB93 is sponsored by Sen. Henry. This bill also enjoys legislature-wide support from Sen. Townsend, Sen. Cloutier, Rep. Jaques, Sen. Blevins, Sen. Ennis, Rep. Bolden, Rep. Hensley, Rep. Mitchell, Rep. Paradee, Rep. B. Short, Rep. M. Smith, and Rep. Wilson.

Since blueprint publication in 2013, the Interagency Committee on Autism (ICA) helped create the task force responsible for supporting all students with ASD and determining the structure and funding for a statewide autism resource network. Task force results include SB92 and SB93.

Get more involved!

For information on how to become an autism advocate, contact Autism Delaware policy & community outreach director Alex Eldreth at (302) 224-6020, ext. 204. Or send an email to alex.eldreth@delautism.org.

Considerations throughout the school years Continued from p. 5

- If your child fixates on a single subject, use this subject to motivate difficult schoolwork. For example, while reading about your child’s favorite subject, add relevant math problems into the story.
- If your child struggles with the concept of numbers, let a toy provide a concrete visual. Grandin’s teacher taught fractions with a wooden apple that was cut into four slices and a wooden pear cut in half.
- If your child experiences motor-control issues with his or her hands, avoid handwriting frustrations by letting your child type on a computer.
- If your child can see the flicker on a computer monitor, try a laptop or flat-panel screen.
- The school bell, public announcement (PA) system, fire drills, scoreboard buzzers, and chairs scraping across the floor are difficult for a child who’s sensitive to loud sounds. Fear of

a recurring sound will escalate the anxiety level of a child with ASD.

- If your child is overwhelmed by visual and sound input occurring at the same time, give him or her the choice of doing the visual or auditory task first.
- If your child sings better than talks, he or she may respond better to instructions in a song format. Or a low whisper may be better tolerated.
- If your child is bothered by visual distractions or fluorescent lights, place his or her desk near a naturally lit window.
- If your child fidgets a lot, help calm his or her nervous system with a weighted vest. And be sure the teacher understands the usage instructions.

For the complete article written by Temple Grandin, visit http://www.autism.com/advocacy_grandin_teaching.

The benefit of hindsight Continued from p. 1

Family SHADE, Family Voices, Autism Delaware, and the Disability Law Project at the Community Legal Aid Society.”

“I can’t think of one single thing that would have made the transition from ‘normal life’ to ‘autism life’ any easier,” says Melissa Stansell. Her son Ryan’s diagnosis was changed from developmental delay to autism shortly after his third birthday. Ryan then transitioned from early intervention services at Child Development Watch to the Charles W. Bush Pre-school. He went part time for several months before being placed in a full-time autism-supported classroom.

“This will truly be one of the most difficult moments in your life as a parent,” continues Stansell. “Maybe knowing we would survive with a new type of normal would have been nice, but that’s hard to imagine in the moment.”

“We didn’t have much support in the beginning,” says Dale Oberender. He and his family lived in another state when his 2-and-a-half-year-old son Eric was diagnosed with pervasive developmental disorder—not otherwise specified (PDD-NOS). “We would have benefited greatly from knowing the special-education process. Although we learned quickly, we stumbled through it at first.”

“Back then,” adds Barb Oberender, “there wasn’t as much known about autism, so we started to educate ourselves. We soon realized that the school system wasn’t going to be able to meet Eric’s needs.

“One day,” continues Barb, “we happened to be watching a TV news story about a school in Delaware for children with autism called the Sussex Consortium Program. We checked it out right away and met with Kris Battaglini, the director at the time.

“We relocated to Sussex County, Eric received a diagnosis of autism from a psychiatrist at the Kennedy Krieger Institute, and we enrolled him in the consortium. Eric was 7 years old by then.”

How do I make the home-school connection?

“Working with teachers to assure that home and school efforts are mutually supportive was not as difficult as it is today,” notes Stomieroski. “Gone are the days when the teacher came to your home to verify that classroom techniques were being carried over—Yes, that actually happened!”

“My son has been in an intolerable classroom situation in the past and does not have the skills to tell me about it,” begins Stansell of her effort to create a home-school connection.



The Stansell family: Amelia, Tom, Ryan, and Melissa

“I have the right to see for myself that his classroom is a healthy environment, so I have shown up unexpectedly to observe. Teachers are not fans of this method, so following my unannounced drop-in, I send a thank-you note explaining that I only have my child’s best interests in mind.

“I am a true helicopter mom,” continues Stansell. “I email teachers often, request conferences and IEP meetings frequently, and when needed, I have asked to observe in the classroom.”

“Lots of communication with the IEP team is essential,” emphasizes

O’Rourke. “Tell the team what you are doing and that you want only for them to understand your child better. Offer that you want to support the team, and ask how you can. Find out how the team prefers to communicate. Tell the team you want to learn how they teach your child so you can carry over at home. And observe whenever you want.”

How do I prepare my child for starting school?

“Luckily,” admits O’Rourke, “I never had to worry about preparing my kids, because they adjust to change better than most people with autism. However, because my kids are lower-functioning, I do a lot to prepare the [school] team for them. Key things I communicate are their likes, dislikes, strengths, and concerns. I meet with the team prior to the new school year.

“Always ask for what you believe your child needs,” advises O’Rourke. “Don’t assume it can’t happen, and don’t be intimidated. Reach out to other parents for help if needed.”

“I verbally communicate my son’s needs with new teachers and meet with them before school starts, if possible. I follow this up with printed copies of *All About Me*, which is a written reminder of my son’s needs, interests, challenges, and his personality,” adds Stomieroski.

“Ryan is pretty easy going,” notes Stansell, “but we always take him to his new school and show him where his classroom will be. Then, we provide the teacher with a one-page brief of the most important things to know about working with Ryan. For example, he uses his iPad to communicate, he’s line-of-sight [which means his teacher needs to keep Ryan in sight at all times], lactose intolerant, and what time to take him to the bathroom.”

“We rely on the professionals at Eric’s school to help prepare him for a new classroom because he’s a visual learner and they’re better equipped at acclimating him to any changes,” says Barb Oberender. Now 20, Eric is facing

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The benefit of hindsight Continued from p. 10

his next major milestone, the transition to Autism Delaware's POW&R program. POW&R is short for Productive Opportunities for Work & Recreation and has been recognized nationally as an effective program for adults on the spectrum.

"Eric is no stranger to the workplace," continues his mother. "He likes to work and has been working with several of POW&R's community partners in the Lewes-Rehoboth area, including Bad Hair Day, Grotto's, Beebe Hospital, and Midway Theater."

What is the best source of parent support?



Jack Stomierski

// My best resource is advice from parents who understand the challenges of autism, and I found this at PAC [parent advisory committee] meetings," notes Stomierski, whose son Jack, now 14, attended the DAP at the Capital School District during the 2014–15 school year. "We all share common challenges, and the more seasoned parents have been a lifeline to me over the years. Plus, I have made lifelong friends."

// I've found Facebook support groups to be most helpful," says Stansell. "I can't always get out of my house to a meeting or gathering, but I can always find five minutes to post or surf on my phone. My neurotypical friends don't get it. I need other moms I can relate to. Some of my most valuable relationships have ended up being with people from across the country who I have never even met!

"I have made the best use of Facebook, not only as a source of support, but also as an educational tool. My Facebook page includes an autism awareness series where I post videos and pictures of 'our autism' so that people can really grasp what our autism looks like—and it's different from everyone else's autism!"

// It wasn't until we moved to Delaware," emphasizes Dale Oberender, "and connected with the parent support group at the consortium, worked with Kris Battaglini in his parent-training sessions, took advantage of multiple home visits by Eric's school team, and connected with the LDAF [Lower Delaware Autism Foundation] and the Autism Society of Delaware that we found our best resources of support." (In 2010, LDAF and the former Autism Society of Delaware merged under the name "Autism Delaware.")

// We connected with LDAF parents who Battaglini referred us to," adds Barb Oberender. "I consider this social network our best resource for support. We have remained actively involved with Autism Delaware since Eric was 7 and are familiar faces at events and programs. Since moving to Delaware, our lives have forever changed for the better as we continue to learn to live with autism."

Where can I find information about a parent coffee hour and support groups to join as well as a recreational outing and social event for my family to enjoy?

At autismdelaware.org!

A conversation with teachers

Parental steps that work

Here, a couple of teachers talk about some steps they've seen parents take that worked well for their children entering new classrooms.

// The most important thing a parent can do for a child with autism in my class," begins high school science teacher Brian Dougherty, "is to communicate with me early on and cultivate a positive relationship. I am always interested in what parents know that can help me make their children comfortable and successful. I think the timing of a dialog is also important since transitions for every child create opportunities for success or failure.

"Of course, a reasonable expectation for one person isn't always reasonable from the other's perspective. I think clear communications regarding what have been hallmarks of a successful environment and triggers for negative behaviors should be clearly communicated to me. A teacher should act responsibly to work to meet the student's needs as permissible."

// The best resources for a parent are IEP [individualized education program] team members, support groups, other parents, and online resources and books," says Lisa Dougherty, a Pennsylvania teacher and educational diagnostician, who works with parents during important transitional times. Dougherty covers a variety of important issues, such as daily schedules, understanding social language, certain areas of comprehension, group work expectations, positive behavior plans, staff communication logs, and home or agency supports.

"For children who are newly diagnosed," Dougherty advises parents, "instruct them in social skills, compromise, and how to access help in different settings. Children need to know to watch the teacher or adult to gauge what is happening socially.

"Teach flexible thinking because things are not always the same. And teach emotional regulation; your child should be able to say how fast his or her engine is running.

"Visit the school cafeteria, nurse, hallways, and special areas. Meet the teachers, and see the classroom. In my school, we offer a 'sneak peek,' which is a big help for parents."



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