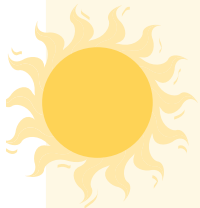


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## Our mission

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



# The Sun

Newsletter

July-September 2011

## The back-to-school issue

### Transitions: a general timeline for the child with an ASD

Change is the one constant in life, but for a family living with a child with an autism spectrum disorder (ASD), change can have a greater impact on home life. The parents of a child with an ASD need to understand the changes—or transitions—faced by their child so they can help the child prepare—and be prepared themselves.



If the child exhibits behavior in areas of concern and is younger than three, contact Child Development Watch. In New Castle Co., call (302) 283-7240; in Kent or Sussex Co., call (302) 424-7300.

If the child is three or older, he or she needs a multidisciplinary development evaluation.

To begin this process, contact your school district's director of special education or the coordinator of the local IDEA Child Find Project.

The school district is responsible for providing free, diagnostic educational evaluations to determine the child's educational needs. Any referral to the Delaware Autism Program (DAP) needs to be made through the school district.

**Note:** In Delaware, the medical diagnosis of an ASD differs from the educational classification of autism. Some children with an educational classification of autism do not receive placement in DAP.

"You should be talking about the supports your child needs to become a participating student in the classroom," advises Heidi Mizell, Autism Delaware's Asperger's resource coordinator, "as well as the services that are available. Have an understand-

Continued on page 10

## The Sun

A publication of Autism Delaware

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Theda Ellis Teresa Avery

Dafne Carnright Carla Koss

Heidi Mizell Jen Nardo

Autism Delaware is interested in a variety of viewpoints about autism and emerging research, but reference to any treatment, therapy option, program, service, or treatment provider is not an endorsement. We publish information only for informational purposes and assume no responsibility for the use of any information. You should investigate alternatives that may be more appropriate for your specific needs.

## From the president



**Rob Gilsdorf**  
President

Moving from a center-based program to inclusion, having unstructured weeks in the summer, or changing schools as our children grow, all bring the uncertainty of change, yet change never leaves our lives.

This year, Judi's and my son Andrew graduated from high school. Our journey has taken 21 years with many more to come, but this year of change for Andrew brought more stress to our home.... Imagine, as you were growing up, if everyone told you what to expect year by year: "Next year, you will go to middle school, then to high school; then, you will graduate at 21." Imagine that their descriptions of what happens at 21 are vague or general: "You will have a job!" "Someday, you will live more independently." You would have questions: "What job? Where? Where will I live? Who will I work or live with? How will I get around? What will happen to my friends from school? Who will be my new friends?"

How often do you hear the saying "Nothing is constant in life except change"? For many of us and our loved ones with autism, change can be frightening.

Thanks to Autism Delaware's POW&R and other employment programs throughout the state, many of these questions are more easily answered, but they are not always certain. Despite the best efforts of many, demand for supported employment and day programs remains high versus the available supply. We are proud of Autism Delaware's role in expanding opportunities for adults with autism. POW&R is running strong in New Castle County and expansion to Kent and Sussex Counties is well underway, greatly helped by a grant from the Longwood Foundation. Things are good and improving.

But what else is uncertain? Without a doubt, independent living options are sorely lacking as our children age. And while our loved ones live with us, how do we keep ourselves together? Personally, I think we can get more access to respite to families of children of all ages.

A wave of perpetual motion is in play. When we make progress in one area, we are reminded we need to make more progress in others. That is what Autism Delaware is about: looking for what needs to change and making those changes a reality. It is our legacy and our future.

The opportunities before us require effort to find innovative independent-living options and better availability and use of

Continued at the bottom of page 8

### A service of Autism Delaware



**PRODUCTIVE OPPORTUNITIES  
FOR WORK AND RECREATION**

**Katina Demetriou**, POW&R Director

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# Helping my son to succeed

by Jen Nardo

Before my son Jake was diagnosed with autism, he was already attending special education through the school district, and preschool and kindergarten were great experiences for him. He had learned his letters and how to write his first name in caps. He was getting some good social experience. Jake even had a friend.

Jake was so successful that, at IEP time [the annual meeting to discuss the individualized education plan] at the end of kindergarten, the school recommended moving my son into the next level for the first grade. As a parent, I was thrilled that my son had made such progress, yet something in my gut told me this move was a mistake: Jake wasn't toilet-trained yet. (The school nurse pushed me hard to train him; the result was a nightmare of tears and screams.) Also, Jake would be one of 12 children in a class with only two adults.

As a first-grader in the new program, Jake started to regress and shut himself off from the rest of the class, spending almost all day on the computer. The teacher worked at including Jake in the class, but she had only so much time in the day and had to divide it among all 12 children. On the other hand, Jake's teacher took a deep interest in him and his needs. In fact, she was the one who recommended an evaluation from the Delaware Autism Program (DAP) that earned Jake a place in the state program headquartered in the Brennen School. Jake started second grade at the DAP, and we never looked back.



**Jake Nardo**

After a few years, I began hearing talk about Jake going to an off-site school. Even though my son was succeeding in school again, my stomach lurched as I remembered the first-grade fiasco. I expressed my concerns to his teacher and tried to listen to her reasons why an off-site school might work for Jake.

To calm myself, I thought about what I had learned. One, Jake's first-grade teacher and I would call each other and talk at school all the time, so I had learned to communicate more often with my son's teacher. Two, as a new volunteer at Jake's school, I would hear what was going on and talk to the office staff—who knows everything about the school—so I had learned to spend more time at my son's school. Three, I had learned to network with other parents whose children are a little ahead of Jake. From these moms, I found out about the principal and the typical children at the off-site school as well as the uniform guidelines. In other words, I learned to ask more questions and be more involved so I know what to expect and can prepare my son. That's my job as Jake's parent.

I think the greatest lesson I learned, though, was about my son himself. He taught me that I should never underestimate him. He may have a setback, but he can step up when he's adequately supported. He showed me that, with some forethought and planning on my part, he can do a lot more. This is how I can help him succeed.

## Walk-Race a success!



To everyone who helped make the 2011 Walk-Race for Autism a success—Thank you! You raised more than \$194,000 for statewide autism programs and services. Thanks to you, we are creating better lives for Delawareans with autism and their families.

## Win a car!

**Only 500 tickets will be sold to raffle off a 2012 Toyota Camry LE. All proceeds benefit Autism Delaware.**

**Drawing: Nov. 19**

**Cost per ticket: \$100**

**Details: [www.delautism.org](http://www.delautism.org)**

**Made possible by Hertrich Toyota of Milford and Autism Delaware**

# Seamless transition into adult life in the community

by **Katina Demetriou**

The transition from school to adulthood is pivotal in the life of any student, but for a young adult with an autism spectrum disorder (ASD), transition of any kind can be challenging and stressful. The transition can be made less confusing and much more successful with careful planning and the appropriate accommodations. In fact, a seamless transition can minimize the impact on the young adult and assure a positive outcome. Here's what needs to occur.

When a student is between 18 and 21 years old, the individualized education plan (IEP) should reflect clear goals for preparing the student for post-school life as an adult. These goals should include employability and independent-living skills, community participation, job sampling, résumé development, and supported employment when appropriate.

Outside of school, planning for post-school life should begin at least one year before graduation, and both the parents and the student need to prepare. The process should allow for a slow transition from school to an adult-services provider.

School personnel need to share their knowledge and expertise with the adult-services provider that, in turn, shares valuable information and knowledge concerning services, employment, social opportunities, and the skills and supports needed for the seamless transition.

From the start, the student needs thoughtful help and reassurance during the move away from the familiarity of the school setting to an unknown adult-services provider. Without this preparation, the scenario exists for backsliding at the most critical time of a young adult's life.

At POW&R, Autism Delaware's adult-services provider, our transition practices begin with our staff observing the student in the classroom, at community vocational sites, and during social and recreational activities. In this step, POW&R staff observes the student's current skill sets and considers the young adult's potential to live in the community and the supports needed.

In the next step, the student works directly with POW&R staff at community sites. Here, the staff sees

how the student learns new tasks and generalizes skills. During this time, interactive training also occurs between the school and POW&R staffs. As a result, the POW&R staff acquires knowledge on how to effectively support the transitioning student. Over the course of the final school year, the school staff fades out, and the POW&R staff takes over.

During this process, the young adult transitions into a post-school schedule. The goal is for him or her to fill the schedule with work, training, an internship, or a volunteer position as well as recreation and social opportunities.

With this step-by-step process, POW&R has a proven track record of seamless transitions for students with ASDs. And we will continue to work at minimizing the stress of transition and to promote a positive outcome.



## Welcome new members!

- |                               |                            |                          |
|-------------------------------|----------------------------|--------------------------|
| Mr. & Mrs. Harry Anagnostakos | Larry & Judith Gladnick    | Felix & Susan Pereira    |
| Christian & Beth Andersen     | Diana Harbert              | Mr. & Mrs. Zadoc Pool    |
| Craig Binetti                 | Jeannette Holloway         | Jin Qian                 |
| Mr. & Mrs. David Blackwell    | Dr. Terry Holton           | Alexandra Roberts        |
| Rich & Peggy Boyd             | John Jaremchuk             | Kristin M. Sanchez       |
| Heather Carver                | Barbara Johnson            | Tiffany Shirley          |
| Jan Dill                      | Wanda King                 | Cora L. Shuford          |
| Tyrone & Bridgett Duncan      | Sherry Long                | Art & Kathleen Smith     |
| Mr. & Mrs. Glenn Gallagher    | Robert & Patricia McDonald | Linda Stoops             |
| Jeffrey & Eileen Gartman      | Susan McElligott           | Mr. & Mrs. Donald Taylor |
|                               | Sandra Merritt             | Heather L. Volkomer      |
|                               | Mr. & Mrs. Mark Miller     | John Willey              |
|                               |                            | Tomara Williams          |

### Benefits of Autism Delaware membership

## Access!

- to the preeminent Delaware agency for autism advocacy as it works to create better lives for Delawareans living with autism spectrum disorders (ASDs) and their families.
- to a range of information and services that meets the varied needs of Delawareans with ASDs and their families.

**Shannon Liew, LPT**

# On social strategies for the student with autism

Supported by an Autism Delaware stipend, Shannon Liew, LPT, attended a two-day conference this spring entitled Social Strategies for the Student/Child with Autism. Shannon wanted information in a couple of important areas concerning children with autism spectrum disorders (ASDs): "I hoped to get some information about iPads and iPod Touches and their various applications. I also hoped to learn how to use them effectively in a typical classroom setting. Students with autism can use these tools not only to communicate but also to interact dynamically and socially with their peers."



Left to right are Shannon Liew, Devin Liew, and Roisin Liew

On the first day of the conference, Shannon listened to Susan Stokes, MA, CCC-SLP, describe the various practical solutions for increasing a student's ability to function independently. "When it comes to talking to a student with an ASD, Stokes said 'Less is more,'" notes Shannon. "I understand this to mean that most children on the spectrum are visually stronger than their peers when obtaining information about the world around them. Although children with autism may imitate others, they lack social awareness in class, so when part of a large class, they may miss the directions. It's best to direct the attention of a child with an ASD to a visual model.

"We all use visual supports—lists, planners, calendars, handouts, and computers—every day," emphasizes Shannon. "These tools are not stepping stones to be weaned from. Our children with ASDs also need daily visual supports." In fact, visual supports are considered a best evidence-based practice (EBP) by The National Professional Development Center on Autism Spectrum Disorders. For more about Best EBPs, visit the center's website at <http://autismpdc.fpg.unc.edu>.

On the second day of the conference, Shannon attended a session with the Minnesota teacher who founded

The Incredible 5-Point Scale. Kari Dunn Buron developed the scale as a tool for students, who have ASDs and are nonverbal, to communicate using pictures. The scale can be used, for example, to address a student's anger and anxiety. Buron also incorporates rhythmic sports and activities (such as archery, fencing, swimming, walking, yoga, and tai chi) into a student's schedule.

The process begins with the student being taught what he or she is feeling. Choices are also presented to calm the child down. These choices include swinging or jumping, leaving the room, listening to music, squeezing a ball, breathing deeply, and counting to ten. Then, the child is taught a "calming tool" to be used when he or she feels angry or anxious. One example of a calming tool: Stop. Close your eyes. Take three slow, deep breaths. Think of your happy place. Open your eyes. Take three slow, deep breaths. Find the teacher.

"Stress and anxiety play a role in triggering unwanted social behavior," explains Shannon, "and yet, learning calming tools is rarely seen on an IEP, behavior plan, or as part of the social learning curriculum." For details on calming tools and The Incredible 5-Point Scale, visit <http://www.5pointscale.com>.

"This conference provided me with the knowledge and insight to meet my original objectives for attending," continues Shannon, "and now, I am ready to get busy helping not only my son, Devin, but also anyone in the autism community who wants to talk to me about social strategies for the student with autism.

"Thank you, Autism Delaware, for providing me with this opportunity," smiles Shannon.

Congress is still in session, and the Combating Autism Act is up for reauthoriza-

tion. Ask your senators and representative to co-sponsor this legislation, which includes funding for autism research, services, and treatment. Autism still receives less research funding than other less prevalent conditions, and as the number of diagnosed children grows, so does the need for better understanding of the cause and better treatment. Efforts to

## Congressional update

make radical changes or cuts to Medicare, Medicaid, and other social ser-

vices were rebuffed at the time this newsletter went to print, but are likely to continue. If you or a loved one benefit from government services that you would like to see continued—IDEA funding, research, Medicare, or Medicaid (which funds adult services)—tell your congressional delegation!



# PARENT PARENT

Written by parents for parents

When my toddler, Casey, received his autism spectrum disorder (ASD) diagnosis last year, my mind flooded with questions about his future: *Would he go to a mainstream school? Would he graduate from college? Get married? Have children of his own?*

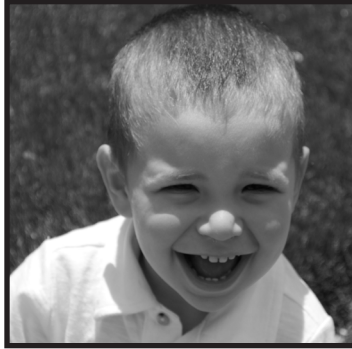
So much of what I envisioned while pregnant with Casey now seemed to fade away.

Then in March, I had to let go of my dream about dropping my eager six-year-old son off at his first day of school. Instead, I found myself peeling my anxious two year old off my leg and pushing him through the door of the Brennen School as the newest member of the Delaware Autism Program (DAP).

I wasn't ready to let go either. I worried: *What if they push Casey too hard? Or not hard enough? And what if the other children are mean to him? Will Casey pick up bad habits from them? Will he be uncomfortable staying in one little room for so long? And what else did I need to know about the whole process?*

Rushed, I began to prepare for this transition. For the teachers, I made a list of the items that helped Casey at home and would probably help him in the classroom. The list included guides to avoid a meltdown (like using the phrase "last one" as a prompt before ending an activity), Casey's sensory needs (like helping him to become more focused by grounding him), and his preferences for paying attention (like drama with added sound effects and enhanced movements).

I learned about the individualized education plan (IEP) process by attending Parent Information Center workshops and talking to my Child Development Watch service coordinator. I found out what other parents did (or wish they'd done) by joining online message boards.



Casey Gilden

And I continued my networking efforts. I joined Autism Delaware and learned everything I could—now.

Knowledge is power, and my effort felt like the biggest and most important cram session of my life. My newfound knowledge gave me the confidence not only to be direct with the DAP administration but also to help meet Casey's needs: Because of his stranger anxiety and separation issues, Casey needed time with me in the classroom, so I made sure this happened. I even observed his class

from the hallway until I was confident the teachers knew what they needed to know about Casey. I may have come off as "psycho mom," but my popularity wasn't important. Casey was.

Casey has now been at DAP for a few months. He is doing well. I find myself relaxing and taking advantage of my free time while Casey is at school. I also appreciate my time with Casey more—instead of struggling to fill the day and getting totally exhausted and overwhelmed. Before DAP, my focus would be on planning the day's activities and making sure Casey and I did enough educational and physical activities; I also worried about his tantrums and sensory discomforts. But now that Casey is getting his needs met at school and my energy doesn't have to be focused on planning and worrying, I can simply be in the moment with him and enjoy our time together. Yes, it's been hard getting used to handing the care of my child over to others. And sharing the duty of educating my son has been unsettling at times, but it has proven best for everyone.

I am truly grateful to the many fabulous teachers and therapists at DAP who are making my vision of Casey's future a reality.

—Cory Gilden

## Advocacy update

Delaware's legislative session has ended. Because this newsletter went to print before the end of session, updates on the budget, insurance, and other bills that Autism Delaware worked on can be found on the advocacy pages at [www.delautism.org](http://www.delautism.org). Or call (302) 224-6020, ext. 204.

**Remember:** Your state legislators work year-round. Contact them anytime, and let them know what they can do to support fair policies and funding for people with autism.

People with autism and the people who love them are the community's best advocates.

—Kim Siegel  
Autism Delaware  
Policy & Events  
Director

# Intense early intervention proves beneficial

The American Academy of Pediatrics is currently recommending that children be screened for autism spectrum disorders (ASDs) by 18 months of age. So when the National Institute of Mental Health (NIMH) funded Geraldine Dawson, PhD (at the University of Washington at the time) to study very young children with ASDs, the goal was to find out what would happen if these children received high-intensity developmental-behavioral intervention.



Dawson and her colleagues began by dividing 48 children (18–30 months old) into two groups. In one, the children took part in a comprehensive developmental-behavioral program designed for children as young as 12 months old. Known as the Early Start Denver Model, the program combines developmental and relationship-based approaches with pieces of applied behavior analysis. ABA itself is a system for breaking down behavior into small, measurable, and teachable units and then using rewards to reinforce the desired behavior.

For example, instead of teaching speech with drills on sounds and words, the Denver model’s therapists began with “talking bodies,” nonverbal communications (such as smiles, gestures, and eye contact) that normally precede speech but which toddlers with ASDs miss. The therapists used ABA techniques to chart progress toward specific goals, but the therapy looked like play: “Infant brains are quite malleable, so with this therapy, we’re trying to capitalize on the infant brain’s potential for learning in order to limit autism’s deleterious effects and to improve their outcomes,” notes the study’s co-author, Sally J. Rogers, PhD, in the UC Davis *M.I.N.D. Institute* publication, *M.I.N.D. matters* (Spring 2010).

During the study, the children received 15 hours a week of clinical therapy, and the children’s parents received training to use another 16 hours (during their daily activities at home with their children). The parents also used any other community-based services they felt were appropriate. (By comparison, the second group of children took part in an assess-and-monitor process. Considered community-based care, ASD intervention and referrals to local community providers were recommended to the children’s parents.)

## The study’s results

The children in the Denver-model group made significant progress over the community-based-care group. By the first year, the IQ of the Denver-model children increased an average of 15.4 points (compared to 4.4

points for the community-based-care children). After two years, the Denver-model children showed improvement in their communication, motor, and daily living skills and other adaptive behaviors. And by the end of the study, seven children initially diagnosed with autistic disorder were diagnosed with pervasive developmental disorder-not otherwise specified (compared to only one community-based-care child).

“The study’s findings suggest,” notes the NIMH website, “that [the Denver model] can help children with ASD achieve better outcomes in terms of IQ, language, and behavioral skills and in severity of their ASD diagnosis than if they receive community-based care. Compared to research on other similar interventions, this study showed greater differences between groups, suggesting that [the Denver model], delivered at a very young age, may be more effective than other approaches” ([www.nimh.nih.gov/science-news/2009/autism-intervention-for-toddlers-improves-developmental-outcomes.shtml](http://www.nimh.nih.gov/science-news/2009/autism-intervention-for-toddlers-improves-developmental-outcomes.shtml)).

“We believe,” continues Rogers in *M.I.N.D. matters*, “that the Denver-model children made more progress because they were involved in carefully structured teaching and a relationship-based approach to learning with many learning opportunities embedded in their play.”

“This is great news for a variety of reasons,” says Autism

## **INSIDE** Autism Delaware

Delaware’s executive director, Theda Ellis, MBA, MEd. “The study clearly shows that intense early intervention can be beneficial. We will be watching for follow-up research to see how children progress over time in school.

“The study also points out the impact that parents can have when appropriately trained and given support and supervision with their children,” adds Ellis. “Children can progress through the spectrum—and we need to make sure they have every opportunity to do so. Delaware’s Early Start Project will be looking more closely at the Early Start Denver Model and how we can bring this early intervention to Delaware.”

## **Autism Delaware**

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**Milton office: (302) 644-3410**

**[www.delautism.org](http://www.delautism.org)**

## Nonprescription meds & the school nurse Learn the school district's policy up front



**Deanna Principe's daughter Samantha and son Joey**

Many children in the autism community rely on nonprescription medication (such as supplements and enzymes) to maintain good health. And recently, Autism Delaware's Deanna Principe found herself facing this issue—and her daughter's school nurse. After some back and forth with the

school, Principe learned the district's policy for allowing the school nurse to give the enzymes to Samantha.

"If your child should need a nonprescription supplement at school," recommends Principe, "ask for a copy of the district's policy so you have everything you need up front."

### *From the president* (continued from page 2)

respite care. We have a group looking into living options. We can always use more help, so please contact Pat Swanson at (302) 777-2171 to participate.

You may not know about some great respite options. Easter Seals is taking the lead with the Delaware Lifespan Care Network created more than seven years ago. Contact Ray Brouillette at rbrouillette@esdel.org or (302) 221-2016 to learn more about respite options for you and your family.

I wish you all an enjoyable summer. Please take the time to

drop me a note at robdelautism@aol.com with your thoughts and suggestions.

*If you need help, ask for it, and when you can lend a hand, lend it.*

## CALENDAR of EVENTS

### July

**2**—Sensory friendly movie: *Cars 2*. Regal Cinemas. 1100 Peoples Plaza. Newark. 10:00 A.M.

**12**—Parent Coffee Hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 P.M.

**15**—Teen/Tween Asperger's Game Night. Autism Delaware main office. 6:30–8:30 P.M. RSVP: Heidi Mizell @ (302) 224-6020, ext. 205.

**19**—Pump It Up Family Event. Pump It Up. 103 So. James St. Newport. 6:30–8:30 P.M. RSVP: Heidi Mizell @ (302) 224-6020, ext. 205.

**28**—Parent Coffee Hour. Holiday Inn Express. 24058 Sussex Hwy. Seaford. 9:00 A.M.

### August

**6**—Sensory friendly movie: *Smurfs, the Movie*. Regal Cinemas. 1100 Peoples Plaza. Newark. 10:00 A.M.

**9**—Parent Coffee Hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 A.M.

**16**—Parent Coffee Hour. Tout de Suite Patisserie. 16394 Samuel Paynter Blvd. Milton. 9:00 A.M.

**19**—Teen/Tween Asperger's Game Night. Autism Delaware main office. 6:30–8:30 P.M. RSVP: Heidi Mizell @ (302) 224-6020, ext. 205.

**20**—Annual Beach Picnic. Cape Henlopen State Park. 15099 Cape Henlopen Dr. Lewes. 11:00 A.M.–4:00 P.M. Food served: 11:30 A.M.–1:00 P.M. RSVP: Deanna Principe @ (302) 224-6020, ext. 213.

**22–25**—Summer Day Camp. The Children's Beach House. Lewes. 9:00 A.M.–4:00 P.M. RSVP: Dafne Carnright @ (302) 644-3410.

**27**—Sensory friendly movie: *Spy Kids 4*. Regal Cinemas. 1100 Peoples Plaza. Newark. 10:00 A.M.

### September

**9 & 23**—Teen/Tween Asperger's Game Night. Autism Delaware main office. 6:30–8:30 P.M. RSVP: Heidi Mizell @ (302) 224-6020, ext. 205.

**17**—Christiana Skating Party. Christiana Skating Center Roller Skating Rink. 801 Christiana Rd. Newark. 5:15–7:15 P.M. RSVP: Deanna Principe @ (302) 224-6020, ext. 213.



**Easter Seals Delaware and Maryland's Eastern Shore Inc.**  
**Are You A Caregiver?**  
**Need A Rest?**  
Saturday Respite Services At Easter Seals Can Help!

We want to remind you of our Saturday respite services at the Easter Seals facilities in New Castle and Georgetown. This service is designed to provide a break for caregivers while simultaneously providing a fun, safe, and stimulating environment to persons who need care or supervision. Any adult from age 18 to 100 is potentially eligible.

Easter Seals offers two options. The first is a four hour option from 10 AM to 2 PM (\$57). The other is a six hour option from 10 AM to 4 PM (\$83).

If you have additional questions about the Georgetown program, contact Ms. Johnette Lanham at 302-253-1100. Future Georgetown dates June 25, July 23, August 27

If you have additional questions about the New Castle program, contact Mr. Ray Brouillette at 302-324-4444. Future New Castle dates June 11, June 25, July 23, August 27

You can keep up to date on Easter Seals respite opportunities by visiting Easter Seals' website at <http://de.easterseals.com>.



## Lego® Club

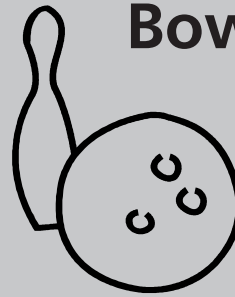
For children who have good communication skills and can follow directions.

**Evaluation required.**

Call Heidi Mizell at (302) 224-6020, ext. 205.  
Or send an email to [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org).  
Or visit [www.delautism.org](http://www.delautism.org).



**Fall 2011 session**  
**Call for dates!**



## Bowling night

Every Wednesday  
5:30–7:00 P.M.

**Bowlerama**  
3031 New Castle Av.  
New Castle DE 19720-2297

To register, email Heidi Mizell at [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org). Or call (302) 224-6020, ext. 205.

## Teen/Tween Asperger's Game Night

For 9–19 year olds with Asperger's syndrome



**Place:** Autism Delaware main office

**Dates:** July 15  
August 19  
September 9, 23

**Time:** 6:30–8:30 P.M.

**Reservations:** Heidi Mizell  
(302) 224-6020, ext. 205  
[heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org)



**Parent Coffee Hour**

*Coffee's on us!*

### Panera Bread

3650 Kirkwood, Wilmington  
July 12 @ 7:00 P.M.  
August 9 @ 9:00 A.M.

### Holiday Inn Express

24058 Sussex Hwy., Seaford  
July 28 @ 9:00 A.M.

### Tout de Suite Patisserie

16394 Samuel Paynter, Milton  
August 16 @ 9:00 A.M.

For more, see the calendar at [www.delautism.org](http://www.delautism.org).

## Go roller skating!

Sensory friendly rink!! Free admission!!!

Sept. 17

5:15–7:15 P.M.

Christiana Skating Center Roller Skating Rink, 801 Christiana Rd., Newark

Skate rental  
\$2.50



## Annual Beach Picnic

**Where:**

**Cape Henlopen State Park**  
**15099 Cape Henlopen**  
**Lewes DE 19958**



**When:**

**August 20**  
**11:00 A.M.–4:00 P.M.**

**Food served:**

**11:30 A.M.–1:00 P.M.**

**R.S.V.P.:**

**Deanna Principe at (302) 224-6020, ext. 213. Or email [deanna.principe@delautism.org](mailto:deanna.principe@delautism.org).**

**Transitions** (continued from page 1)

ing of what your child’s needs are. Don’t get stuck on a diagnosis or label.”

Once your child has been evaluated, an individualized education plan (IEP) should be created. Members of the IEP team should include

- the parents,
- at least one regular-education teacher if the child is or may be participating through the regular-education system,
- at least one special-education teacher,
- a representative of the local school district who is qualified not only to provide—or to supervise the provision of—specialized programming that meets the unique needs of children with disabilities but is also knowledgeable about the general-education system and the availability of resources in the local school district, and
- a person who can interpret the instructional implications of the evaluation results.

The team collaborates on long-term planning, assures that due process is followed, meets at least once every 365 days to determine the child’s educational needs (according to state and federal law), provides information relevant to the child’s progress, creates IEP goals and measurable objectives, analyzes evaluations, and documents the decisions in the IEP. For more about IEPs, visit the Parent Information Center of Delaware website at [www.picofdel.org](http://www.picofdel.org) or the Delaware Department of Education website at <http://regulations.delaware.gov/AdminCode/title14/900/925.shtml#TopOfPage>.

**Between early intervention and elementary school**

The second transition involves the child’s move out of the early-intervention program and into elementary school. By law, schools are required to provide a free, appropriate public education in the least restrictive environment (LRE) that is appropriate to each child’s needs. With the appropriate supports and services, your child can succeed in the classroom.

**Note:** When choosing a classroom setting for your child, consider the LRE as well as your child’s developmental needs. For example, does your child learn better by listening or doing?

**Between elementary school and middle school**

The third transition—out of elementary school and into middle school—is often the most challenging for children with ASDs. Why? They have difficulty making friends. Because a child with an ASD struggles with empathy and social cues, the child cannot tell the

difference between teasing and sincerity, which is a major step in adolescent progress.

Another reason is the “hidden curriculum,” the unwritten rules that govern the social atmosphere of your child’s school. (For more, see the box below.)

“Have your child shadow a sixth grader in the same school your child will be attending,” suggests Mizell, “and learn about rotating classes so you can explain the process to your child. Help your child by beginning to work on the organizational skills and self-advocacy needed to successfully negotiate middle school.

“And ask the IEP team or the school counselor what the other children are wearing and talking about,” continues Mizell. “Armed with this information, you can help your child to fit in better at school.”

“Transitioning to middle school can be difficult,” adds Dafne Carnright, Autism Delaware’s southern Delaware service coordinator, “because of all the changes in school. The schedule is very different. Your child will

Continued at the top of the next page

**Defining the hidden curriculum**

Generally, a “neurotypical” child intuitively picks up positive social skills with little effort or instruction from others, but a child with an autism spectrum disorder (ASD) may be unaware of the unwritten social rules governing the world we live in. The variables change across age, gender, culture, and location, ranging from socially acceptable dress to which backpack to carry to school in childhood, and in adulthood, from how to disagree with your boss to behaving appropriately in a public restroom. For this reason, a child with an ASD often needs direct instruction on the unstated social rules.

In the book *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations*, Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan explain the hidden curriculum, how it affects people living with ASDs, and how to teach it to them. The authors give numerous examples of different situations, including airplane trips, bathrooms, birthday parties, clothing, school, and slang.

Another resource that helps teach the hidden curriculum is a flip calendar called the *2011 Hidden Curriculum One-A-Day Calendar*. This resource explains a new item each day of the year and comes in a child’s, adolescent’s, and adult’s version. It’s available at Amazon.com.

**Transitions** (continued from page 10)

have several different teachers throughout the day and may have to use a locker for the first time. The building itself is likely to be much larger. And the activities in physical education may present more challenges. All of these differences may need to be examined in the context of your child's abilities and needs. Consider what supports will be needed for each area, and make sure they are in place prior to the start of middle school so all parties are aware of what needs to happen."

On the other hand, you are now more familiar with your child's learning style. Use this knowledge when discussing your child's IEP. Also, discuss the tools used to teach your child organizational skills and how to break down large assignments. "Your child should be part of this process," says Mizell. "Find out how your child works in a group setting. Does your child contribute to the process, or is your child letting everyone else do the work? Whatever the answer, the appropriate supports and services need to be added to the IEP."

**Between middle school and high school**

The fourth transition is into high school. The choices include the diploma track and the life skills track. For the child on the diploma track, the IEP should address the supports your child needs to succeed in college or in the working community after high school. Work with your IEP team to determine what is needed and the best way to deliver it.

"Understand what your child needs and what will be provided to help prepare your child for college," notes Mizell. "If your child needs more time to prepare, consider some creative scheduling. Set up a class schedule that gives your child extra time. Even if your child is a student in special ed, he or she can walk through graduation with the rest of the class. The point is to focus on what your child needs to best prepare for college life."

For the child on the life skills track, focus on developing work and independent-living skills, including communication skills. Make sure your child has the opportunity to try a variety of jobs so your child can discover what he or she enjoys and does well.

At the same time, start looking at adult-services providers, such as Autism Delaware's POW&R. (For information about this transition, see the article on page 4.) Available services vary widely—as does the knowledge and understanding of the needs of young adults with ASDs. To become educated on the topic, attend service provider fairs and visit some of the available programs. Ask what the participants do during a typical day, how many have paying jobs, and about the program's experience with people with autism.

Also, consider applying for social security insurance for your child and the need for establishing legal guardian-

ship and power of attorney for your adult-child's affairs.

Finally, become familiar with the state's legislative process. Your child's entitlement to services ends at the age of 21; after 21, services are dependent on state funding. The challenge grows every year to add services for young adults with ASDs. As a parent, you need to advocate for these services.

Nationally, adults with ASDs are sitting home and losing their hard-earned skills from school. Fortunately for Delawareans with ASDs, many are working and living happily in the community. Getting to this point takes time and planning—and the courage and means to face a lot of change—but seeing our young adults grow, improve their skills, and live independently makes the effort worthwhile.

**For more information on transitions, contact Heidi Mizell at (302) 224-6020, ext. 205, or [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org).**



The southern Delaware staff gratefully accepted more than \$800 from The Firm Fitness Center in Rehoboth Beach. The funds were raised during a pentathlon challenge in April to benefit Autism Delaware. Left to right are the center's manager, Ted Dabbs; the top women's finisher, Marisol Timmons; Autism Delaware's Amanda Jackson (administrative and event assistant), Dafne Carnright (service coordinator), and Melissa Martin (POW&R coordinator); and the top men's finisher, Dan Matta.

**Autism Delaware**  
**So. Delaware office**  
**(302) 644-3410**



924 Old Harmony Rd.  
Suite 201  
Newark DE 19713

www.delautism.org

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Becoming a silver, platinum, or lifetime member will make you a part of a select group of individuals that has demonstrated special leadership and a deep commitment to making a significant difference in the fight against autism. As a leader in the support of autism and autism research, you will receive special recognition in our newsletter or other documents.

Please make your check payable to Autism Delaware.  
Mail payment and application to:  
Autism Delaware, 924 Old Harmony Rd., Suite 201, Newark DE 19713  
To pay by credit card: Visit www.delautism.org. And click the "Join today" button at the bottom of the left-hand menu.  
All membership fees and contributions are tax-deductible to the fullest extent allowed by law.

My membership fee is ..... \$  
I would also like to contribute this amount ..... \$  
Total amount enclosed ..... \$

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

Name(s): \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone: (h) \_\_\_\_\_ (w) \_\_\_\_\_ Email: \_\_\_\_\_  
I am a:  Parent  Family member  Service provider  Educator  Medical professional  Individual with autism  Other (Please describe): \_\_\_\_\_

Enroll me in the following category:  
 Individual \$20  Family \$25  Professional \$50  Silver \$100  Platinum \$300  Lifetime \$500  
 I am a new member.  I am renewing my membership.

# Annual membership application