

The Sun

Newsletter

April-June 2013

Walk for Autism Put the fun in fund- raising!

How do you have fun while raising funds for Autism Delaware's statewide programs?

Get the answer at autismdelaware.org. Click the Walk for Autism button.



Our mission

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



Leisure time!

One of the gifts of childhood is leisure time over summer vacation. That's when children discover new interests, learn new skills, and make new friends. In a safe and supportive environment, children can also experience independence and risk-taking.

"All these factors are important to children with autism," notes Heidi Mizell, Autism Delaware's resource coordinator in New Castle County. "I suggest you do a little research, see if a program is something your child might be interested in, and then talk to the program coordinator to make sure your child's needs can be met."

For some questions to ask a program coordinator, see the article on page 10, *Considering summer camp*.

The following list includes some programs to consider for your child:

Autism Delaware

Summer day camp, swim, golf

Milton DE: (302) 644-3410
autismdelaware.org

Teen/Tween game night

Newark DE: (302) 224-6020
Milton DE: (302) 644-3410
autismdelaware.org

Camp Atlantic

Delaware program, McLean VA
(703) 863-9485; campatlantic.org

Dragonfly Forest, Inc.

Conshohocken PA
(610) 298-1820; dragonflyforest.com

List continues on page 10, bottom right



How would you like to enjoy leisure time yourself this summer?

"Caring for someone on the spectrum," notes parent Cory Gilden, "demands a lot of time and energy. Fortunately, a system of respite enables caregivers to take a break."

Defined, *respite* is the temporary care of an individual on the spectrum, which gives the primary caregiver a short interval of relief. In Delaware, respite care—or reimbursement for respite care—is available in a number of ways:

Delaware Autism Program

Is your child enrolled in the Delaware Autism Program (DAP) through the Christina, Brandywine, Caesar Rodney, Capital, Seaford, or Cape Henlopen School District? If so, your child is eligible to receive respite care at a discounted rate. This rate is based on a sliding scale according to your child's qualification for a free or reduced-cost

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The Sun

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Cory Gilden 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.

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On being equal to the challenge

It comes as a shock to no one who reads *The Sun* to hear that rates of autism are rising dramatically across the country and around the world. Just last year, the Centers for Disease Control and Prevention (CDC) announced the new prevalence rate as one in 88. In Delaware alone, we experienced a 546 percent increase in the number of public school children with an educational classification of autism over a 19-year period from 1991 to 2010.

What does this mean? As many families as there are currently in need of support in our state, many more are coming. As a community, we must work together to create an even better place for all of them to work, play, and live.

The question of how we do that is discussed daily here at Autism Delaware, as I know it is within other organizations across the state. For the answer, we need to look directly and specifically at the need—both now and in the future—and work together to meet it.

Our entire community is called to address essential questions like these:

- How will we make certain that the highest quality education will be available to students with autism as their numbers increase?
- What will the parents of the newly diagnosed need most, and how can we best support them?
- Where and how can we best serve children with more severe behaviors who may not be able to stay in

their homes?

- How do we encourage more professionals in the autism field to practice in Delaware?



Teresa J. Avery, MBA
Executive Director

Of course, the many questions are not limited to issues surrounding childhood. We must also think carefully about how our children are prepared for the adult world, the types of work environments that are best for each of them, and the residential service options that should be available to them.

These are only some of the issues on my mind as I write this piece in late January. Our organization is in the midst of creating our next strategic plan. Our goal is to determine how we will move forward to meet the need in the next five years.

One thing is certain: It will take our entire community—nonprofit organizations, educators, state departments and leaders, corporate partners, autism professionals, the individuals with autism themselves, and their family members—to meet the growing need. But I believe that all of us, working together, are equal to the challenge.

A service of Autism Delaware



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Is the school responsible for a 12-month program or ESY?

by Lauren O'Connell Mahler, Esq., McAndrews Law Offices, PC

12-month program—Delaware law has a unique provision found in Title 14, Chapter 17, section 1703(e) of the Delaware Code, which states that educational programs must be conducted on a 12-month schedule for students identified with autism (as well as several other disabilities). The Delaware Code further states that a school district may extend school attendance from the regular 1,060 hours per year up to 1,426 hours for programs for students identified with autism. Enrollment beyond 180 days per year in any program is on a voluntary basis, and applications must come from the parent, guardian, or other person legally responsible for the student. The student's individualized education program (IEP) has a box that should be checked if the student is eligible for a 12-month program under this provision.



While the federal Individuals with Disabilities Education Act (IDEA) does not deem students identified with autism to be automatically eligible for a 12-month program, a student with autism may qualify for a 12-month program under IDEA if the IEP team determines that a 12-month program is necessary to provide the student with an appropriate education where he or she will have the opportunity to make meaningful progress.

ESY—Students who do not qualify for 12-month programs may still be eligible for extended school year (ESY) services. Under the federal IDEA, ESY services must be provided to a student at no cost to the parent if the IEP team determines that the services are necessary to provide the student with an appropriate education based on that student's individual needs. The services must address the child's unique needs and cannot be limited in their type, amount, or duration. Federal IDEA does not set specific criteria for determining whether a child is eligible for ESY.

The Delaware Code, however, sets forth the following specific criteria that IEP teams should consider when determining whether a student qualifies for ESY:

- Without ESY services, will appropriate and meaningful progress on the IEP goals and objectives be achieved?
- Does the student have a consistent pattern of substantial regression in critical skill areas over the summer break?
- Will attaining a nearly acquired critical skill be significantly jeopardized over the summer break without ESY services?
- For students whose IEPs contain vocational or employment goals and objectives, would paid employment opportunities be significantly jeopardized if training and job coaching are not provided during the summer break?
- Do any special or extenuating circumstances exist that justify provision of ESY services?

ESY services should be tailored to the student's individual needs and goals as identified in the IEP; therefore, if the student needs social skills and appropriate and meaningful progress has not been made or the student is likely to regress during the summer, then the summer program should include a social skills program. The same applies to all other special education and related services (occupational therapy, for example).

What are Delaware's PTAs and PACs doing?

President of the Brennen School parent-teacher association, Cory Gilden—"The Brennen School PTA has been very busy this year. We've organized events and courtesies for staff, including a winter appreciation breakfast and raffle, spring appreciation lunch and raffle, 'Hot Pot of Soup' Fridays, the reinforcer closet, staff surveys, and book donations to classrooms. For the community, we've held book fairs and a holiday-giving tree. For parents, we've provided information about respite, after-school care and nursing, and Care Notebooks, and arranged for speakers from Practice Without Pressure, Medicaid, and the Brain Balance Program. For families, we organized a hayride, events at Pump It Up and Chuck E. Cheese's, picture day, and swim grants for students. The Brennen School community can look forward to another scholastic book fair the week of April 29 as well as a spring picnic and train ride on the Wilmington & Western Railroad in May."

President of the John S. Charlton School parent advisory committee, Karen Mackie—"We decided to keep the PAC and PTA separate, and voted to work together with liaisons attending each other's meetings, especially since one-third of Charlton's population has a diagnosis of autism.

"Also, we are working vigilantly to keep parents informed. Autism Delaware's southern service coordinator, Dafne Carnright, spoke at our November meeting about health insurance reform and the autism summit. And the Center for Disabilities Studies ACCESS Project's Judi MacBride and the Delaware Department of Education's Brian Touchette spoke at our January meeting about the design and implementation of the DCAS Alt 1.

"Parent turnout for both meetings was great. We hope to formulate a way to hear parental feedback because the Charlton PAC wants to be the voice of parents in these times of tremendous change."

PARENT PARENT

Long-time newsletter contributor and mother of an adolescent son with autism and fragile X syndrome (FXS), Jen Nardo shares what she learned from Cindi Rogers, a friend with two young adult sons who also have autism and FXS.

If you would like to learn more from Cindi, visit her blog at mrsrogersfxneighborhood.blogspot.com.

Children with autism can be overwhelmed by the change from the regular routine of the school year to summer school. And their anxiety over the change can create all kinds of behavior problems and make your time together difficult.

To enjoy the summer and each other, Cindi created a chart that included goals for the summer and days off as well as time to get outdoors and exercise.

Simply writing words on the summer chart, though, made no sense to her boys. And "time to exercise" meant nothing to them either. So Cindi came up with a creative way not only to help her sons understand what they'd be doing but also to get them to exercise: She used visuals instead of words and noted a different activity at the same time every day. She snuck in the exercise by parking about a half mile away and announcing "Today, we are walking to the library," "Today, we are walking the dog," or "Let's walk to get some ice cream."

Over time, Cindi also created visuals for a scavenger hunt on their walks. When the boys found all the items, they were "all done" with their time to exercise and could go home.

Once a week, Cindi and her sons shopped at the grocery store, dropped off mail at the post office, visited friends or the zoo, went to the movies, met Dad for lunch, or swam. Although the activities varied, they fell on the same day to provide structure.

As the boys got older, Cindi built time into each week to teach her sons new skills or tasks, such as household chores.

With focus on structure and routine, Cindi eased her sons' anxiety about the summer break and strengthened their familiarity with tasks and locations. Realizing these benefits, Cindi also created a "vacation" chart, a "what we do at the zoo or library" chart, and a "Fridays off in the summer" chart.

For more about creating visuals for a summer routine, see the article below.

Structure for success

"Child and adolescent development experts point out," writes Jolene Roehlkepartain in her article entitled *Why structure is important*, "that structure is key for raising successful kids. The beauty of a structure (when you design it well) is that it gives your kids stability and flexibility at the same time. Step into any child care center, school classroom, or after-school program, and you'll find a structure. Kids know what to expect at the beginning of their time together, what happens in the middle, and how a leader or teacher wraps things up" (parentfurther.com/blog/the-importance-of-structure).

Structure is especially important for children on the autism spectrum, notes Autism Delaware's resource coordinator, Heidi Mizell: "Many children with autism experience anxiety when they don't know what to expect. Having a schedule tells a child what to expect and helps the child feel more secure in the world. Add structure to the summer break by setting up a daily schedule. For ideas, talk to your child's teacher or therapist.

"A schedule can also help motivate your child to do some-



thing he doesn't want to do," adds Heidi. "Get past the 'I don't want to' reaction by showing your child a fun activity to do after the unwanted task is completed."

For children who communicate better with pictures, Heidi suggests using visuals: "For a template, ask your child's teacher or therapist. Then, you can show your child a picture or image of each of the day's scheduled activities. Make sure your child can see and understand the sequence of events. You can reduce power struggles by displaying the schedule where your child can look at it.

"A schedule change can make a child's day *go south* quickly," adds Heidi, "so when you need to make a change, be sure to explain why to your child. If your child is a worrier, consider explaining later rather than sooner."

Finally, keep to the summer routine as much as possible during the weekend and on vacation. "If your child normally gets up at 7:00 in the morning," explains Heidi, "continue the seven AM wakeup.

"Keep bedtime close to the same hour each night, too. Every child is happier when functioning on enough sleep."

Disability law and the power of words

Autism Delaware Adult Issues Committee members David Graham and John Swanson attended a Delaware State Bar Association seminar in December 2012. Entitled *Disability law: Its impact on our children and families—The power of words*, the seminar began with an historical overview, looking at the drive toward equal rights and protections and the evolution of language during the 20th century.

Supporting the current social model, the World Health Organization provided some critical definitions for the terms *impairment*, *disability*, and *handicap*. “An impairment does

not become a disability until we experience it as such,” explain Graham and Swanson in a synopsis of the seminar. “Even then, it is a societal decision to handicap the individual because of the impairment. Further, defining people exclusively by their impairments—*crippled*, *retarded*, *mentally ill*—has been modified by a ‘people first’ rhetoric. For example, where we used to say ‘He is autistic,’ today we say ‘He has an autism spectrum disorder.’”

For a copy of the Graham and Swanson article, visit autismdelaware.org.

OAR on IEPs

The Organization for Autism Research (OAR) publishes a guide entitled *Life Journey through Autism: Navigating the Special Education System*. Reprinted here is the opening section on IEPs. The complete guide is reprinted with OAR permission in Autism Delaware’s new parent packet. To get a packet, visit autismdelaware.org.

One of the first phrases to come to mind when talking about special education is the individualized education program, whose abbreviation, IEP, instantly becomes one of those... you will remember for life. Mention IEPs to parents and teachers alike, and their reaction tells the story. The term conjures up unpleasant memories and is frequently met with a groan. For someone new to the special education world, the IEP and its process can seem daunting and, at times, excessive. No matter how so, IEPs are important.

The IEP provides a description and action plan for what you and the school mutually

determine that your child requires in terms of services and supports necessary to learn. It is a prerequisite to receiving special education services. At best, when well written, these legal documents assure that your child receives what he or she needs for success. Conversely, if not done well, they can become lengthy documents that involve inordinate amounts of time, are ineffective, and do not serve your child well.

How can you avoid IEP challenges? Collaboration is the goal and intent of the Individuals with Disabilities Education Act (IDEA). Work with the school professionals, understand the IEP process, keep accurate and detailed records, and prepare for each meeting as if it’s a final exam. If you do these things, you will be better positioned to make sure that your child’s IEP successfully assures him or her full access to the free and appropriate education (FAPE) in the least restrictive environment (LRE) envisioned by IDEA.

A few weeks before your child’s IEP is set to expire, you should be contacted by the school to set up a time for a new IEP meeting. Depending on your school’s policies, you may receive a letter or a phone call. IEP meetings are usually scheduled during school hours, which can be difficult for parents. If your work schedule is inflexible, many schools are willing to schedule meetings before school hours. Be advised that IEP meetings scheduled outside of school hours may result in absent team members. When the IEP meeting time has been agreed upon, you should request that draft IEP goals are sent to you at least three days before the meeting. These goals will be drafted by your child’s case manager or teacher with input from the other IEP team members.

The IEP draft is a working document, so be sure to read over the draft goals and come prepared to provide feedback at the meeting. You may also want an advocate or another person who knows your child well to review the goals....The other sections of the IEP should be written collaboratively, though team members may have individually drafted information they think is important to include in the document.

Make sure to arrive at the IEP meeting a few minutes early to allow time to complete any visitor registration at the main office. Your child’s case manager will usually run the meeting, but any team member may be in charge. The leader will introduce everyone on the IEP team and have them sign in so as to maintain a record of attendance. From here, the team will progress through the document segments as described in the following section.

After reading this section, you will have an in depth understanding of all the parts of an IEP.



INSIDE Autism™ Delaware

Autism Delaware Summer Day Camp

Would your child enjoy camp but struggle with the overnight stay?

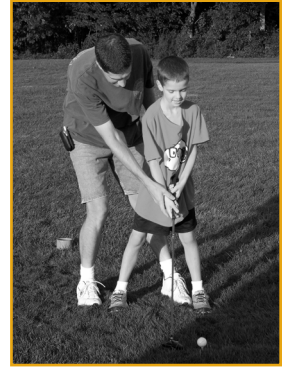
Consider day camp: Autism Delaware can accommodate 30 children at the Children's Beach House in Lewes—August 19–22 from 9:00 AM to 4:00 PM.

Designed specifically for children with autism spectrum disorders (ASDs) who will be enrolled in grades 3–11 for the 2013–14 school year, this day camp offers a range of fun and educational activities, such as kayaking, sailing, swimming, a low ropes course, and arts and crafts. Throughout each activity, emphasis is put on communication, social skills, and self-esteem, so each child works on personal skills and has the opportunity to try new things.

Download an application at autismdelaware.org.

Autism Delaware Junior Golf Program

Is your child interested in golf or in learning a new skill? Golf pro and coach Butch Holtzclaw will be teaching golf techniques and personal skills at The Rookery Golf Course in Milton. Dates and times (the spring-summer of 2013) will be announced later.



Designed for youth with ASDs aged 8–21, the six 30-minute sessions will provide instruction in putting, chipping, driving, and full swing as well as work on golf etiquette and values, such as respect, confidence, responsibility, perseverance, courtesy, and sportsmanship.

For updates—Email delautism@delautism.org, and request to be added to the Autism Delaware Google group.

Autism summit kicks off development of strategic plan

The Center for Disabilities Studies (Center)—with help from Autism Delaware and the Delaware Department of Education—presented an autism summit in June 2012. Part of an action that began months earlier, the summit began the process of creating a comprehensive statewide plan. As a strategic plan, it would improve and coordinate the supports and services needed by Delawareans with autism spectrum disorders (ASDs) across their life spans.

Funded by the U.S. Department of Health and Human Services' Health Resources and Services Administration, a two-year grant was awarded to develop the plan. Facilitating the process is Center staff member Annalisa Ekbladh.

Since the summit, three work groups have been developing goals and objectives in education, adult issues, and healthcare. Activities have focused on gathering information on the challenges and needs experienced by parents and caregivers.

Also targeted were stakeholders (Delawareans with ASDs). Surveys went out to three separate populations: school-aged children, adults, and adult self-advocates.

Many categories of need were reviewed. The surveys' results were analyzed by the Delaware Education Research and Development Center, an independent University of Delaware-based organization that provides services in educational research, evaluation development, and policy analysis. The reports detailed the impact on the family, diagnosis and follow-up care, barriers and limitations, employment challenges, services, and unwanted outcomes. Among the specific findings:

- Parents of school-aged children expressed a need for increased training in social skills.
- Access to respite care is lacking, especially for the caregivers of adults with ASDs.
- Medical and dental practices struggle to handle the behaviors of children with ASDs during regular office visits.
- Adults with ASDs do not receive routine dental care, because it is not affordable and not covered by Medicaid.

According to the Center's Annalisa Ekbladh, all three work groups recognized the need for ongoing training and technical assistance—grounded in evidence-based practice—for teachers, direct support professionals, and healthcare professionals: "We all want a well-trained cadre of professionals, who desire to work with people with autism and have the skills and support they need to do their jobs."

Join us!

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Autism
Delaware

Jacob's Jems

A self-employment success story

"Is being self-employed and managing your own business possible for an individual with an autism spectrum disorder?" begins Melissa Martin, coordinator of Autism Delaware's southern services for adults with ASDs. "Yes! Many people with ASDs share the same traits, talents, and ideas as many small business owners: flexibility, a strong support network, and the ability to come up with, create, and supply innovative products and services. Plus, when the right individual is matched to the right opportunity—and the environment is supportive—the result will inevitably be successful."

One example is Jacob's Jems, a new business in southern Delaware owned by Jacob Sipple.

As a participant of Autism Delaware's adult vocational services program (familiarily called POW&R), Jacob honed a talent for shredding any type of material; unfortunately, when frustrated, Jacob also exhibited self-injurious behavior. Both factors were addressed by POW&R staff member Tina Williams and Jacob's parents, Barry and Angie Sipple. As a team, they realized that shredding was a job Jacob was good at and could get paid for doing. But how could shredding be taken to another level, using many of Jacob's other skills and abilities? And was Jacob able to diminish his self-injurious behavior?

As a result of this collaboration, the idea for recycling shredded material was born. The shredding would be sold as beautiful gift bags as well as filler for shipping and gift baskets.

Jacob, his parents, and POW&R staff reached out to Autism Delaware's community partners for material to shred. For

creative help, the team solicited donations from the Cape Artists Gallery and other Sussex County artists. With this artistic support, Jacob's Jems had the images and printed cards needed to accompany the gift bags.

With continued support from his team—including Autism Delaware Clinical Director Susan Peterson, PhD, BCBA-D—Jacob also enhanced his ability to successfully use his functional communication skills while decreasing the frequency of his self-injurious behavior. Success appeared imminent when Jacob secured an office space at Hickman Overhead Door in Milford.

Several business plans later, the team launched Jacob's Jems. Jacob is busy these days, shredding, packaging the shredded material, inserting cards and envelopes into the bags, and sealing and delivering the gift bags to retail sites—and earning an income as the owner of a small business. The entrepreneur is currently creating gift bags for Easter and hide-and-seek bags with a unique gift presentation as well as taking orders for custom shredding jobs.

Where can you find Jacob's Jems?

- Milton: Autism Delaware, Dawn's Country Market, Thomas David Salon
- Milford: Hickman Overhead Door, Sandy's Country Gifts, Country Expressions, Angelucci Studios and Artists' Gallery, The Mail Center
- Lewes: Java Bytes, Kids Ketch Toys and Fashions

POW&R™

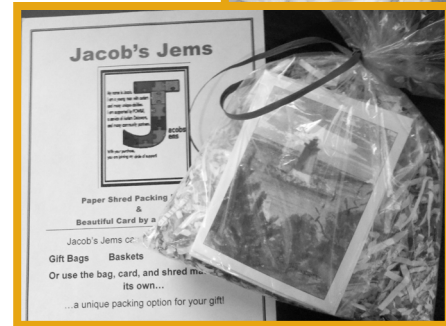
PRODUCTIVE OPPORTUNITIES
FOR WORK AND RECREATION

Katina Demetriou,
Director

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Jacob Sipple



jacobsjems@gmail.com

Thanks to all the businesses, artists, and supporters of Jacob's Jems for providing Jacob with the opportunity to be engaged in meaningful, productive work that he enjoys.

—Angie and Barry Sipple

Golf sponsorships

Sponsor a tee at the 2013 Drive for Autism, and your company name will be seen by the nationally known news and sports figures playing May 30 at the DuPont Country Club in Wilmington.



Picture your company name here!

Also available:
Big benefits for corporate sponsorships!

For details:
driveforautism@delautism.org

DSM-5 update

Attention deficit hyperactivity disorder (ADHD) is one of the conditions that occurs most frequently in children. And in children with autism, about 30 percent have symptoms of ADHD, notes Madeleine Johnson in her October 2012 article, *New rules allow joint diagnosis of autism, attention deficit*; however, until the American Psychiatric Association updated its **Diagnostic and Statistical Manual of Mental Disorders (DSM)** recently, “a troublesome passage...prevented doctors and researchers from describing ADHD and autism as disorders that can occur together” (<http://sfari.org/news-and-opinion/news/2012/new-rules-allow-joint-diagnosis-of-autism-attention-deficit>).

Promising the elimination of this passage, the fifth edition of the manual, **DSM-5**, is due out May 2013. As a result, improvements should be seen in the treatment of accurately diagnosed children with both disorders. “Under the **DSM-5** guidelines,” continues Johnson, “doctors can directly analyze whether children with a primary diagnosis of ADHD and some autism symptoms might benefit from strategies designed for autism—such as social, speech and occupational therapies. Likewise, children diagnosed with autism who show symptoms of hyperactivity, inattentiveness, or impulsivity may benefit from treatments designed for ADHD.”

Another example of frequent co-occurring diagnoses involves Asperger’s syndrome. “Young children with Asperger’s syndrome are prone to develop mood disorders,” writes Tony Attwood in **The Complete Guide to Asperger’s Syndrome** (Jessica Kingsley Publishers: 2007), “and some seem to be almost constantly anxious, which might indicate a generalized anxiety disorder” (p. 17). Attwood estimates that “65 percent of adolescents with Asperger’s syndrome have an affective or mood disorder,” the most common being anxiety and depression (p. 129).

“These numbers might sound extremely high,” says Susan L. Peterson, PhD, BCBA-D, the clinical director at Autism Delaware, “but a diagnosable mood disorder makes sense when you consider the challenges people with Asperger’s have with social reasoning, conversation skills, different learning styles, and bullying.

“A professional qualified to treat mood disorders and another to treat Asperger’s, working in collaboration, can treat both conditions effectively,” assures Peterson. “Of course, this collaboration would work for ADHD and autism, too.”

CALENDAR of EVENTS

April

- 3, 10, 17, 24**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 9**—Care Notebook Workshop. Easter Seals. 61 Corporate Circle. New Castle. 6:00 PM. *Register:* Heidi Mizell at heidi.mizell@delautism.org.
- 9**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.
- 11**—Parent coffee hour. Espresso-N-Ice. Gateway West Shopping Center. 1030 Forrest Av. Dover. 9:00 AM.
- 12**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 15**—Parent coffee hour. Hampton Inn Middletown. Lobby. 117 Sand Hill Dr. Middletown. 9:30 AM.
- 17**—Smart Cookie Day. Legislative Hall. Legislative Av. Dover. 2:00 PM.
- 17**—Sussex First Responders Training: *Working with persons with autism in urgent care situations*. CHEER Community Center. 20520 Sandhill Rd. Georgetown. 9:00 AM.–12:00 NOON. *Register by March 22:* (302) 644-3410.
- 20**—Walk for Autism. Cape Henlopen State Park. 42 Cape Henlopen Dr. Lewes. 9:00 AM. *Register:* autismdelaware.org.
- 26**—Teen/Tween game night. Autism Delaware Milton office. 6:00–7:45 PM. *Register:* Dafne Carnright at (302) 644-3410.
- 27**—Walk for Autism. Bellevue State Park. 800 Carr Rd. Wilmington. 9:00 AM. *Register:* autismdelaware.org.

May

- 1, 8, 15, 22, 29**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 9**—Parent coffee hour. Holiday Inn Express. 24058 Sussex Hwy. Seaford. 9:00 AM.
- 10**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 14**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.
- 25**—Sensory friendly movie: *Epic*. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. *Register:* Amanda Gordy at (302) 644-3410.
- 31**—Teen/Tween game night. Autism Delaware Milton office. 6:00–7:45 PM. *Register:* Dafne Carnright at (302) 644-3410.

June

- 5, 12, 19, 26**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Register:* Heidi Mizell at heidi.mizell@delautism.org. Or call (302) 224-6020, ext. 205.
- 11**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.
- 14**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Register:* delautism@delautism.org.
- 18**—Parent coffee hour. Georgia House Restaurant. 18 S. Walnut St. Milford. 9:00 AM.
- 22**—Sensory friendly movie: *Monster University*. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. *Register:* Amanda Gordy at (302) 644-3410.

Parent Coffee Hour

Panera Bread

3650 Kirkwood Hwy.
Wilmington
April 9 @ 9:00 AM
May 14 @ 7:00 PM
June 11 @ 9:00 AM

Join us!

Espresso-N-Ice

Gateway West Shopping Center
1030 Forrest Av., Dover
April 11 @ 9:00 AM

Hampton Inn Middletown

Lobby
117 Sand Hill Dr., Middletown
April 15 @ 9:30 AM

Holiday Inn Express

24058 Sussex Hwy.
Seaford
May 9 @ 9:00 AM

Georgia House Restaurant

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



2013 Auction for Autism New location!



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

Saturday, November 16
6:00 PM

*This year's theme:
Superheroes for Autism*

2013 Blue Jean Ball Mark your calendar!

Saturday,
September 21

Rehoboth Beach
Convention
Center



Smart Cookie Day

April 17, 2013
2:00 PM

Legislative Hall
Legislative Av.
Dover



*Share cookies—and your
story—with your legislators.*

April is Autism Awareness Month.



**Advocate!
Educate!
Fundraise!**

For ideas, visit autismdelaware.org.

Teen/Tween game night

For 9–19 year olds
with Asperger's syndrome

Place: Autism Delaware™
Newark office

Dates: April 12
May 10
June 14

Time: 6:30–8:30 PM

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

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

Spring 2013 season

For 9–14 year olds with
Asperger's syndrome

Place: Autism Delaware™
Milton office

Dates: April 26
May 31
June TBD

Time: 6:00–7:45 PM

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

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

Considering summer camp

Are you thinking about sending your child or sibling with autism spectrum disorder to summer camp? Here are some considerations for getting the best fit for you and the child.

Ask for recommendations. Start with the child's teachers or specialists. After all, they have gotten to know the child and may have an idea for reinforcing a piece of the individualized education program (IEP) over the summer.

When you have the names of some recreational or camp sites, contact the program coordinators. Here are some questions to ask:

Is the camp considered residential, specialty, inclusive, or a day camp? Does it offer indoor or outdoor activities that the child is interested in?

Can the child play sports or interact with animals? Can the child choose what to take part in? And is adapted equipment available if needed?

Does the child have a personal quirk? If the child needs to wear socks in the pool, for example, be sure to tell the counselors to avoid a poolside meltdown.

Is the camp accredited with the American Camp Association (ACA)? An ACA-accredited camp is set up according to specific standards concerning operation, program quality, health, and safety. For details, visit acacamps.org.

Is the campus accessible to the child's physical needs? Unless the camp has a religious affiliation, it must satisfy accessibility standards set by the Americans with Disabilities Act (ADA). But if your child needs paved pathways to navigate safely and the camp has only gravel or dirt trails, then this camp is not a good fit.

If the child wants to go away to camp, overnight accommodations need to be considered. These can range from tents

and tepees to cabins. Can the child even tolerate an overnight stay with new tent mates? Are the accommodations air-conditioned? Do they provide quiet space for down time? And are the accommodations staffed at night?

Also consider the size of the group the child will be joining. A child who is accustomed to only four people in a classroom needs to be acclimated before joining a camp with 30 children.

The people taking care of the child need to be considered, too. Who are they? How thorough is the staff application process? What is the minimum age requirement? What qualifications are required? Does the camp perform background checks on all staff? And how will the child's personal information be shared with staff?

Is the staff required to complete any training relative to the camp? Important certifications include life-guarding, CPR and First Aid, and emergency management.

Also, is the staff trained in disability awareness and camper care? Staff needs to be able to address all of a child's special needs.

What is the staff-to-camper ratio? If the child needs constant one-on-one supervision but the staff-to-camper ratio meets the need for only minimal assistance (1:3), then this camp is not a good fit.

What type of medical support is available? The ACA recommends an on-site licensed physician or registered nurse. In case of injury or illness, will you be notified?

In addition to physical safety, the child's emotional and social safety should be considered. How will the child's behavioral plan be addressed? How is undesirable behavior defined and addressed? Does the camp have a clear definition of acceptable behavior?



Autism Delaware Summer Day Camp

August 19–22
9:00 AM–4:00 PM

(302) 644-3410
autismdelaware.org

Leisure time! continued from p. 1

Camp Fairlee Manor

Chestertown MD
(410) 778-0566; de.easterseals.com

United Cerebral Palsy of Delaware

Camp Manito

(302) 764-2400
ucpde.org/summer-camps

Camp Lenape

(302) 335-5626
ucpde.org/summer-camps

Mary Campbell Center

Karleen O'Brien
Director of Children and Youth
(302) 762-6025
marycampbellcenter.org

Camp Barnes

Special Olympics, Newark DE
(302) 831-3480; sode.org

Variety Club, Rockland DE
(302) 397-0017; varietyphila.org

The above considerations were gleaned from *Discover Camp*, a publication of The National Center on Physical Activity and Disability, copyright 2010, Board of Trustees of the University of Illinois.

Leisure time! continued from p. 1, column 2

lunch. For example, if your child pays full price for lunch at Brennen School, the DAP-provided respite currently costs \$3.81 per hour. For students who get reduced-cost lunches, respite costs \$2.28 per hour; free lunches, \$0.76 per hour.

Each school has its own process for connecting you with the respite coordinator, so call your DAP school to begin. Be sure to note the specific dates and times you want the respite for your child.

For each student, respite is limited to 24 hours per month. This allotment expires at the end of each month, but an additional seven days are also available throughout the year.

Your request will be sent to DAP-employed professionals and paraprofessionals in the respite program to see who's available. If you would rather speak personally to a potential provider (such as your child's teacher, for example), you still need to contact the respite coordinator to make proper arrangements.

Delaware Lifespan Respite Care Network

The Delaware Lifespan Respite Care Network helps you connect with respite care providers. Call (302) 324-4444, and speak with someone personally. Or visit delrespite.com, and type in your criteria.

You will choose from a list of providers who offer respite at different locations, times, and prices. You may also name your own provider, such as a family member. Be sure to apply well before the respite care is needed.

The network offers financial assistance in the form of a scholarship. The scholarship recipient may receive about \$500 in a calendar year. This amount can be less if a large demand is made on respite services.

Nursing agencies

If an individual on the spectrum needs daily medical attention, nursing agencies provide short-term care but often have small staffs in high demand. Your name may be added to a waiting list. Be sure to apply well in advance of when the care is needed.

To find an agency that meets your needs, check the Delaware Lifespan Respite Care Network. Or directly contact an agency, such as Nurses 'n Kids, Bayada Home Health Care, Maxim Healthcare Services, Interim HealthCare of Delaware.

Some Medicaid waivers may cover the cost of a nursing agency. To see if you qualify, call Delaware Family Voices at (302) 221-5360. Ask for the director, Ann Phillips.

Division of Developmental Disabilities Services

The Delaware Health and Social Services' Division of Developmental Disabilities Services (DDDS) reimburses the cost of respite care for anyone but the primary caregiver. But to receive reimbursement, you must be registered with DDDS. The process (which is similar to registering with Medicaid) involves a case worker and the completion of a large packet of information. Once you are registered, you can submit a request for respite reimbursement.

The rate of \$10 per hour can be used to pay for a respite provider or for a program, such as summer camp. To receive this reimbursement, email the DDDS coordinator each month; list the specific dates and times the respite provider was needed. DDDS will then send a check for that month's respite care.

For more information about DDDS respite services, call Bonnie Hummer at (302) 933-3145. Or visit dhss.delaware.gov/dhss/ddds.

Getting more out of respite care

Some respite funding can be used for more than the cost of care; it can also cover camp fees for children on the spectrum. "I know several families who used some of their children's yearly respite funding from DDDS to cover the fee for the Autism Delaware Summer Day Camp," notes the camp's coordinator, Autism Delaware Southern Service Coordinator Dafne Carnright, MS, LPCMH. "And some families used funding found through the Delaware Lifespan Respite Care Network.

"If you want to pay camp fees with respite funding, be sure to tell the agency when you apply," advises Dafne.

"I have also talked to families who don't use respite care for a variety of reasons, but I recommend that families investigate respite options early in their journeys," adds Dafne, who's also the mother of a child on the spectrum. "It's important for both parents and children to have time away from each other. Rested and recharged, you take better care of your loved ones—and your child learns how to function without you. I mean, consider this: What if you have an emergency and your child needs to spend time away from you—and never has before! Imagine your child's reaction.

"I suggest you try some time off just once," continues Dafne. "For your own peace of mind when hiring respite care, ask about the training and experience of the providers, and follow your instincts. Start with one or two hours of respite. Maybe go grocery shopping by yourself. Before you know it, your child will be enjoying new, positive experiences, and you will be enjoying much-needed breaks."



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Helping People and Families Affected by Autism

Raise funds for the Walk!

Now more than ever, we need your help.

Sign up today for the 2013 Walk for Autism, and help raise funds for the programs and services needed statewide by Delawareans with autism spectrum disorders.

Raise \$100 or more, and win a prize!

Statewide event!

Cape Henlopen State Park
Lewes

Saturday, April 20

Bellevue State Park
Wilmington

Saturday, April 27



Sign up at

autismdelaware.org