

The Sun

Newsletter

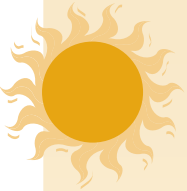
Spring 2020

New in this issue!

Ask a parent p. 3

This new column features a question that one of our parents has wanted to ask another parent—and another parent answers!

If you would like to ask or answer a question in a future issue of *The Sun*, send an email of interest to carla.koss@delautism.org.



Our mission

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



Plan ahead for summer

Frankie and Jake Nardo enjoying vacation

In 2017's spring issue of *The Sun*, parent Jen Nardo shared a few of her life lessons on how to vacation so it's relaxing. Included is how to choose the best destination for your family as well as the best way to get there. (To read this article, visit AutismDelaware.org, choose the Stay Connected page, scroll down to the issue on mental health and autism, and then scroll to page 8.)

In this issue:

- Jen shares what she has learned about sleep-away camp.
- Parent Cory Gilden covers traditional day camp for kids who don't need one-on-one services.
- Parent Virginia Sticinski describes the ins and outs of two popular theme parks that have disabilities programs.

Autism DelawareSM

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Heidi Mizell Jen Nardo Virginia Sticinski

If you prefer to be removed from *The Sun's* mailing list, please call or mail a request to the Newark office (noted below) or email your request to carla.koss@delautism.org.

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Surprise!

This one little word most accurately describes what it feels like when I'm reminded to start planning summer activities for my kids. Granted, I'm a longtime manager of a range of special-needs programs, so I know what the experts say about planning: "The earlier, the better!" Yet I am surprised by how few days have passed since I was surprised last year. (*How can it be that time of year already?*)

So, here I am, listening to a repeating list of unanswered questions in my head and feeling the accompanying anxiety:

Can my family afford to go someplace special this summer? If so, where? (And who has time to go someplace anyway.)

Can I find something appropriate and inclusive for my kids to do?

What if I don't plan anything? Does this make me a bad father?

More importantly, what will my wife say if I apparently forget to plan something?!

For parents with children on the autism spectrum, the time for planning is crucial. The reality is, summer programs for children with special needs fill up quickly.

Plus, parents need to research the options before choosing the program that best suits their children. This step can be time-consuming as the parent visits a couple possible camps, talks to the responsible staff members, and introduces them to what makes his or her child so unique.

If respite funds are needed to help cover the cost, the state's process takes

time, too. If you need to start this process, email the Delaware Division of Developmental Disabilities Services at DHSS_DDDDS_RespiteRequest@state.de.us. Tell them that you need to apply for respite funds for your child and to start the eligibility and approval processes.



Brian Hall, MSW
Executive Director

Meanwhile, this issue of *The Sun* provides some information that may help answer your list of questions. Three parents with children on the spectrum share their personal knowledge and experience with day and sleep-away camps and amusement parks. They also point out specific considerations when looking into inclusive experiences. Altogether, their articles can help you create more opportunities for a successfully inclusive summer experience.

This issue is also the first with a revised presentation. Using feedback from our staff and parent-mentors, we chose a format with more graphics and white space while maintaining readability standards.

We hope you agree with our choice. Please take a moment to share your thoughts. Send them to carla.koss@delautism.org.

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Ask a parent is a new column that presents a question from a parent, grandparent, or caregiver—and an answer from parents in our community.

As a parent with a child on the autism spectrum, have you wondered how another parent would handle your particular situation? Or maybe you'd appreciate hearing about another parent's success story and how it was achieved.

To offer a question or your availability to draft an answer, send an email of interest to carla.koss@delautism.org.

Q

What are some effective ways to deal with procrastination? My grandson's response to being asked to wash his clothes is "Later." Nagging does not benefit either of us.

—Diane Isaacs

Newark grandmother responsible for young adult in Autism Delaware's adult services program

A

Since this young adult is washing his own clothes, he sounds pretty high-functioning, which can present some different and difficult obstacles. Maybe the grandmother could consult with her grandson's team or some other professional to talk through how to set and enforce boundaries, incentivize and reinforce behavior, and use available tools, like social stories, for instance. Some consistent, persistent, patient efforts can work wonders without having to get caught in the endless cycle of nagging.

—Marcy Gause Kempner
Parent of adult son in Autism Delaware's adult services program

My only thought is to withhold something desirable until the job is done: TV or computer time, a favorite snack, whatever he likes. This particular problem hasn't been much of an issue for my family—probably because we're all procrastinators!

—Claire Priester
Parent of working 34-year-old son on the autism spectrum

I have found an effective reply to be "Okay, but you won't be having breakfast (or lunch, dinner, a snack) until your clothes are in the dryer." Since doing chores can seem purposeless, it's important to make the chore into something that needs to be done before he can engage in a preferred activity. "After you do this, then you can do that" works for my children. You will need to stick to your guns though: The first time or two that you use the *this now-then that* stipulation, your child may end up eating dinner at 10:00 PM but will soon realize that you mean what you say.

Other things to try:

- Tie prompt compliance to his allowance: He earns so many dollars if the chore is completed within a certain time frame; if not, a portion of his allowance will be held back.
- Use the token system: By earning a set number of tokens each time he complies with a request, he'll earn points toward a trip to a favorite location, a meal in a restaurant, or an item he is interested in.

The hope is that, eventually, your child will no longer need these supports and will do the chores as a matter of course. My daughter does; my son is not there yet—but my fingers are crossed that he will get there!

—Karen L. Tuohy
Parent of an adult son and daughter on the spectrum

Accommodating theme parks



by Virginia Sticinski, MEd

Are you planning a family vacation this spring or summer but you're concerned that amusement parks may be too much stimulation for your child on the autism spectrum?

As a mom of four boys, two of whom are on the spectrum, I get it. Amusement parks are great for most kids, but many parents write off parks for fear of overstimulation. And then there are the long wait times!

Don't despair! Some of the most popular theme parks offer special accommodations to families like ours.

Continued on p. 5

Hersheypark

A local favorite, Hersheypark offers Fast TrackSM passes to guests on the spectrum at no additional charge. Guests plus as many as three members of the party can skip the general queue and enter the Fast Track lines, which offer substantially shorter wait times.

To get a Fast Track pass, guests and their families must check in with Hospitality Services (at the main entrance) and complete the Attraction Accessibility Questionnaire. Then, a representative at Hospitality Services will determine the level of accommodation needed for each guest. Families do not need to bring confirmation of a child's autism diagnosis.

For more information on accessibility at Hersheypark, check out <https://www.hersheypark.com/info/accessibility.php>, or call (717) 534-3900. You can also enjoy a live chat with a Guest Services representative on Facebook Messenger.

Disney Parks & Resorts

Disney Parks—including Magic Kingdom Park, Disney's Hollywood Studios, Disney's Animal Kingdom, and Epcot—offer generous accommodations for individuals on the autism spectrum.

Disney's Disability Access Service (DAS) is available to eligible guests and as many as six members of the party. This option allows guests to check into a ride and get a return time, which means they can skip the longest lines and return for a shorter wait. Eligibility is determined on an individual basis by Guest Relations, which is located at the park entrance.

Families do not need to bring confirmation of a medical diagnosis.

Some restrictions apply. For example, eligible guests may only use this option one time per ride and for one ride at a time.

For more information, interested families can contact Disney Guest Relations at (407) 824-4321.

Busch Gardens

Busch Gardens includes Aquatica, Busch Gardens Williamsburg, Busch Gardens Tampa Bay, and SeaWorld Orlando.

Busch Gardens' Special Access and Ride Accessibility Program (RAP) are for guests with disabilities and as many as six members of the party.

An accessibility guide can be found on the Busch Gardens Tampa Bay website at <https://buschgardens.com/tampa/park-info/accessibility-guide>.

For Busch Gardens Orlando customer service, call (813) 884-4386.

As die-hard roller-coaster enthusiasts, my family has visited many of these parks, so we can vouch for the services they offer. The ride-return option can save hours of wait time.

In addition, these parks offer quiet rooms for guests with sensory needs, and special park ambassadors support their guests with disabilities. We found that the quiet rooms provide a nice break when the noise and crowds prove too much, and the park ambassadors were both friendly and accommodating. Quiet rooms and park ambassadors are found throughout the parks or at designated Guest Services locations. Ask a park representative for a specific location.

Though the accommodations at these parks are generous, you must request these accommodations in person at each of the listed parks; none will confirm an accommodation over the phone.

The line at Guest Services is usually long during peak seasons, so be prepared to spend about 30–60 minutes in line. It sounds like a long wait, but believe me, it's worth it. And you only have to do this once, even if you're planning to visit the park on multiple days.

So go ahead, and plan that vacation to a theme park. With just a little extra effort and some research, you can be sure everyone in the family will get the most out of the time you spend together.

Sun contributor Virginia Sticinski, MEd, is a social sciences instructor at Delaware Technical Community College, Stanton, a valued member of the Autism DelawareSM newsletter committee, and the parent of four sons. Two are on the autism spectrum.



The Centers for Disease Control and Prevention (CDC) suggests that parents and caregivers tailor the general recommendations for keeping children safe by considering these bullet items:

- *Know and learn about what health concerns or special conditions are unique for their child.*
- *Plan ways to protect their child and share the plan with others.*
- *Remember that their child's needs for protection will change over time* (<https://www.cdc.gov/ncbddd/disabilityandsafety/child-safety.html>).

For more information, visit the CDC website at <https://www.cdc.gov/ncbddd/disabilityandsafety/child-safety.html>. The CDC also provides a list of resources to help you define how to keep your child safe.

Is your child ready for sleep-away camp?

by Jen Nardo



Clip Art

Unlike a day camp, a sleep-away camp provides accommodations for overnight stays for a week or two. And for years, I worried about my son's well-being at sleep-away camp and safety while sleeping in a bunkhouse. As a child with autism spectrum disorder (ASD), Jake might have a meltdown when he didn't want to take part in some activity or eat the food he was served. Of course, I also worried that he would miss me—and knew for a fact that I would miss him.

Jake was in high school before I felt ready to let him try sleep-away camp. At that point, I'd seen that he could take care of himself. Because he would rather I do everything for him, I knew he would benefit from more independence. So, I signed Jake up for Easter Seals Camp Fairlee.

Why I like this sleep-away camp

Easter Seals Camp Fairlee is a traditional summer camp for children and adults with all types of disabilities or special needs.

According to the website, there are generally two camp participants for every one counselor (<https://www.veryspecialcamps.com/summer-camps/Easter-Seals-Camp-Fairlee-2012.html>). A one-to-one option is also available for children and adults with ASD. Of course, I appreciated the depth of hands-on support available to Jake.

The camp director also took the time to explain how the camp finds and vets the counselors and maintains dietary needs, daily schedules, and bathing facilities for the campers.

Questions that helped me determine my child's readiness for sleep-away camp

- **Has the child ever stayed overnight somewhere with you (at a hotel, a family member's home)?**
- **Has the child stayed overnight somewhere without you?**
- **How does the child act without you around?**
- **How does the child cope with new experiences?**
- **Has camp been presented as a positive and fun experience?**
- **What camp activities might cause stress for the child and what would the child prefer?**
- **Would another year to mature make a difference in the child's readiness? Or would a day camp be a better way to start?**

How I know sleep-away camp is good for my son

I have seen my son mature and gain independence. His behavior at camp is different from how he acts at home. He hates showers at home but takes them at camp. And he eats whatever they serve. He also sleeps on a lower bunk or a single bed in a room with other campers and counselors. He has kayaked, ridden a horse and zip line, climbed a rock wall, gone swimming, made crafts, enjoyed a hayride, and danced to music.

How I know sleep-away camp is good for me

As hard as it was to walk away the first time I dropped Jake off at camp, I was glad to get in some much-needed respite time.

If you're a parent thinking about sending your child to camp, make sure you plan to do something nice for yourself, your spouse, or your other children. It could be a sit-down meal at a nice restaurant you've been wanting to try, a few days at the beach, or quiet time to renew your soul.



Clip Art

How I prepared my son for sleep-away camp

- We sang camp songs in music therapy.
- We looked at online photos of camp.
- We visited camp a few times for an hour or more.
- We told social stories about camp and described camp activities.
- I reminded Jake over and over that I will pick him up when camp is done.

How I prepared the camp counselors

I wrote a couple of pages explaining what Jake liked and his potential triggers.

Parent-mentor Jen Nardo has been developing ideas and writing articles for *The Sun* for 12 years. She continues to be a respected contributor to the newsletter and is a longtime volunteer for Autism DelawareSM events as well as the parent of two sons. One is on the autism spectrum.

Here's a resource that may help.

Rudy, Lisa Jo. *Challenges and Tips for Summer on the Autism Spectrum*. Medically reviewed by Sarah Rahal, MD. **Verywell Health**. Updated on January 17, 2020. <https://www.verywellhealth.com/challenges-and-tips-for-summer-on-the-autism-spectrum-4163801>.

Summer day camps are a great way to expose children with autism to social and learning experiences in a more relaxed environment. Day camp offers continuous opportunities for interacting socially, practicing strength and motor skills, and reinforcing life skills. Most camps have semi-structured environments where campers can enjoy some independence while also feeling supported. Importantly, campers also build community and a sense of belonging through shared experiences, such as singing, playing games and sports, and enjoying inside jokes and playful rivalries.



by Cory Gilden

To promote a culture of inclusion at camp,

parents and camp staff can do many things. Parents can speak with directors well in advance of camp to get details about what to expect. Being honest about concerns is crucial because minimizing or omitting a child’s needs could set him or her up to fail.

Summer Adventures Camp director Victoria Elasic advises parents to share as much as they can with staff, including the child’s

- likes and dislikes,
- strengths,
- fears,
- warning signs of stress or overstimulation and a safe activity for the child if he or she gets upset,
- any sensory, communication, or social issues that can be anticipated, and
- important medical and dietary needs.

“Use your best judgment about your child and what you think will be a good fit,” says Victoria. “If you move forward with a program and your child has a plan in place from the school year with accommodations, this is very helpful for the summer camp to have to provide your child with the needed support.”

Parents can also help their children prepare for camp:

- Visit the camp website.
- Tour the camp, or go to the camp open house.
- Learn the camp’s schedule.
- Create social stories, or talk through what-if scenarios.
- Practice coping skills.
- If a child is able, talk to the child about his or her anxieties and expectations.

Finding a day camp that is a good fit for a child with autism can be challenging. If a child has one-on-one support in school or needs constant supervision, notes Victoria, this child may need a more specialized environment. If a child expresses resistance to going to camp, then it may be best not to push it. And if the camp has very large groups or no previous experience working with a camper with autism, these may be warning signs that the camp is not a good fit for your child.

“Depending on the child’s sensitivities,” continues Victoria, “camp can be overwhelming. Summer day camp programs can be quite loud, and the children are typically more animated at summer camp as compared to a regular school day, so this environment can create an overwhelming sensory experience for a child with autism.”

Online resources for more information

A Camp for Everyone! A Guide to Including Children of All Abilities in Summer Camp Programs (developed by United Cerebral Palsy of Delaware, Inc.)—<https://ucpde.org/wp-content/uploads/2015/06/a-camp-for-everyone-a-guide-to-including-children-of-all-abilities-in-summer-camp-programs.pdf>

Tips to Integrate Children with Autism into a Day Camp (North Shore Pediatric Therapy, Ill.)—[https://www.nspt-4kids.com/healthtopics-and-conditions-database/autism-](https://www.nspt-4kids.com/healthtopics-and-conditions-database/autism-spectrum-disorder/tips-to-integrate-children-with-autism-into-day-camp)

[spectrum-disorder/tips-to-integrate-children-with-autism-into-day-camp](https://www.nspt-4kids.com/healthtopics-and-conditions-database/autism-spectrum-disorder/tips-to-integrate-children-with-autism-into-day-camp)

Find a camp (American Camp Association)—<http://find.acacamps.org>

Leading the Way: Autism-Friendly Youth Organizations (a guide to help community organizations make their programs more inclusive of children with autism)—<https://www.autismspeaks.org/tool-kit/leading-way-autism-friendly-youth-organizations>

How I helped create a positive day camp experience for my son

by Cory Gilden

Sometimes a kid benefits from the more loosely structured and active environment of summer camp. This is true for my son Casey. Like most kids with autism, Casey loves a schedule and his quiet downtime, but my free-range son also likes to explore and experience new things. So, once he was in grade school, I started looking at summer camps.

Choosing a summer day camp that suited my son's needs did not happen instantly.

I had to consider the typical issues for choosing a camp, such as location, cost, and a child's preferred hobbies and sports. And then I had the added considerations of Casey's unique dietary needs, sensory issues, and sensitivities to materials and environments. For example, Casey does not function well in the heat for too long, but I did not want him stuck inside all day either. He thrives when he can switch between environments and take part in new experiences in new places.

I could tell that my quest to find a summer day camp for Casey was different from other parents' when camp directors hesitated in answering my questions: "My son is on a special diet. Can you microwave his lunch?" "How will staff react if they can't understand what my son is saying?" and "Can I get a daily report from the counselors about camp activities and any social interactions?"

(Okay, so we're high maintenance.)

Having spent several summers as a camp counselor myself, **I knew that transparency about my son's needs would help camp staff** anticipate and respond to Casey more appropriately. So, every year I give his camp director, nurse, and counselors a one-page info sheet about him:

- his diagnoses and differences to expect because of them,
- his preferences, such as being

given notice before an activity ends and playing on his tablet to calm down,

- his dietary and medical needs, and
- my contact information.

To make all this information seem less imposing, I top the sheet with a cute photo of Casey's smiling face.

I finally found a day camp that I thought would be a great fit.

A friend of Casey's went there, too. Plus, the camp director and staff supported inclusion and were willing to work with us.

First, I toured the camp so I could ask questions about staff-to-camper ratios, schedules, transportation for field trips, and so on. **Then, Casey and I toured the camp together.** This step familiarized him with the setting, which helped him feel more comfortable and excited about the pending experience.

On the first day of camp, Casey skipped into the building—and I crossed my fingers. Six years later, Casey still loves going to camp. Returning campers and counselors now know him well, welcome him into the group, and help him have a great summer.

And Casey helps them learn that—with a little preparation—kids on the autism spectrum can enjoy a positive camp experience.



Casey Gilden enjoys swimming and all the other typical summer camp activities at Summer Adventures Camp through Hockessin Montessori School. He also takes part in field trips. At the Brandywine Zoo, he listened intently to camp intern Sarah Walker as she explained the benefits of snakes in the environment. Standing behind Sarah is intern Emily Culkin.



Sun contributor Cory Gilden is a former teacher, longtime autism advocate, and a research assistant with the National Leadership Consortium on Developmental Disabilities, earning her doctorate from the Joseph R. Biden, Jr., School of Public Policy & Administration, as well as the parent of a son with autism.

INSIDEAutismSM
Delaware

New inspiration for family social groups



We have the opportunity to connect with families who attend our family social groups and share the experience of our amazing family support staff thanks to new grant funding from the Division of Prevention and Behavioral Health Services [DPBHS].

This funding allows Autism Delaware to provide dinner and childcare to make it easier for families to attend.

You get to talk to another parent who has been in your shoes while enjoying a meal and an evening of support and relaxation while your kids are being cared for: What more could a parent ask for!

—Annalisa Ekbladh
Autism Delaware policy
and family services director

Introducing Table Talk (o Sobremesa, en español).

This family-networking dinner is

- facilitated by trained family members of individuals with autism.
- taking place in each county.
- including conversation and childcare provided by Let's Play.

Interested in attending?

Contact your Autism Delaware family support provider (FSP) or family navigator.

At each dinner, you will

- gain insight from the challenges faced by other families and learn how they succeeded.
- be able to share in a safe and confidential environment.
- develop supportive relationships.
- find local resources available to you and your family.

Don't have an FSP or family navigator currently working on your behalf? Call Autism Delaware intake coordinator Melanie Matusheski at (302) 224-6020, ext. 219, and ask to be assigned one.

The new family social group model will also

- continue to offer the Spanish-speaking support groups and grandparent support groups as usual.
- add a quarterly virtual support group for the families of newly diagnosed children.
- discontinue coffee hours in New Castle and Sussex Counties because of lack of interest.





Social recreation for our youth and young adults

Autism Delaware’s social recreation supports youth and young adults on the autism spectrum while also giving them the opportunity to socialize with others. Their time together may be structured or unstructured around a specific activity.

Our goal, says Autism Delaware policy and family services director Annalisa Ekbladh, is to provide opportunities for individuals and families to have a fun and successful recreation or social experience and explore new activities.

For more information

AutismDelaware.org/
Get Help/Support & Activities

Autism Delaware social recreation

- bounce night
- bowling
- roller skating
- beach picnic
- holiday parties
- train rides
- Blue Rocks games
- junior golf

Autism Delaware summer beach day camp

For 30 youth on the autism spectrum who ranged in age from the third grade to 17 during the 2019–20 school year

August 17–20, 2020
9:00AM–4:00PM

Children’s Beach House
1800 Bay Av., Lewes

Application deadline
May 1, 2020



Remember “those lazy, hazy, crazy days of summer” when you were a kid? This opportunity is available to our kids with autism spectrum disorder (ASD) through Autism Delaware’s summer beach day camp.

Applications are available at <https://www.delautism.org/get-help/support-and-activities/social-recreational-opportunities>.

For more information about Autism Delaware’s day camp, contact Autism Delaware community engagement specialist Louise Doe at (302) 224-6020, ext. 215, or email her at louise.doe@delautism.org.



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Helping People and Families Affected by Autism

Give autism a hand!

**Create your own fundraiser,
and help extend our reach
so we can support more families.**

Here are some examples of current fundraisers:

- DeLAWAREness (a dance showcase)
- The Ride to Know (a motorcycle-poker run)
- Art For All (a paint night)

Here are some other ideas:

- dodgeball
- car wash
- bake sale
- blue jean day at work

**The only limit
to fundraising is
your imagination!**



For more information, contact:

David Woods
Director of fund development & engagement

- (302) 224-6020, ext. 206
- david.woods@delautism.org

AutismDelaware.org