

The Sun

Newsletter

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Mental health and autism

In this issue of *The Sun* are articles and essays written by individuals with autism spectrum disorder (ASD), the parents of children with ASD, and professionals in the autism-mental-health community. They help explain the challenges inherent to individuals with ASD and the mental-health issues they face as well as the long-term impact on families. Below, we start with an explanation of mental health and ASD.

Explaining mental health and ASD

Sun contributor Jessica K. Mueller, PsyD, is a trainee in the Leadership Education in Neurodevelopmental Disabilities (LEND) program and psychology fellow at Nemours/Alfred I. duPont Hospital for Children's Division of Behavioral Health.

When you think about the term "mental health," what comes to mind? It can bring up different ideas and images, including stressors, anxiety, depression, or going to therapy. Now, think about the word "autism." What comes to mind? Do your thoughts overlap at all around mental health and autism spectrum disorder

Now, imagine that you are an individual with ASD who is required every day to engage in various social rituals that do not come naturally to you:

- knowing when and how long to make eye contact
- understanding how to enter and leave a conversation
- determining if others are interested in playing or talking to you
- listening to something that does not interest you

Navigating these various social demands and expectations of everyday life can present a host of challenges. Like doing mental math, the effort can wear you down and bring out mental-health concerns, such as anxiety, behavioral problems, and depression. Having ASD also does not exempt people from worrying about doing things correctly, experiencing difficulty communicating wants and needs and acting out, and feeling sad as a result of confusion about social interactions. All are common among individuals with ASD.

Acknowledging the overlap

Acknowledging these mental-health challenges is the first step. Individuals with ASD can benefit from support and understanding from their families and,

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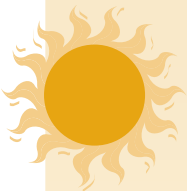
(ASD)? For some, these two areas may seem vastly different. Others see significant overlap with the struggles faced by individuals with ASD and those in the mental-health system.

Defining the overlap

Imagine that you are not good at math. Now, imagine that multiple times every day, you are required to do math in your head. Sometimes, the mental math is simple, but other times, it is more complex. The daily grind can wear you down.

Our mission

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



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Addressing mental healthcare

Mental health is a serious issue for many individuals and families affected by autism in our state. Research indicates that more than two-thirds of children with autism may have complicating mental-health issues that range from anxiety to obsessive compulsive disorder.

Unfortunately, the system that has developed over decades to provide supports for those with developmental disabilities (like autism) is separate from the system that developed to provide support for those with mental-health challenges. In fact, clinical practitioners in these two areas largely learn very different clinical languages beginning in the earliest days of their training.

As a result, individuals with autism (and their families) often find it difficult to get the mental healthcare they need to address issues like anxiety and depression. And when our kids and adults with autism go into crisis, they may be taken to mental-health facilities with well-meaning and well-trained mental-health professionals who have had little opportunity to learn about autism.

This situation is not the fault of the mental-health practitioners. Where we find ourselves today is the result of decades of separation between the two systems, and everyone will need to work together to bridge the gaps and create a fully supportive environment for individuals with autism.

Much work is being done as I write. For example, Delaware's Division of Substance Abuse and Mental Health has worked hard to offer to professionals in the field multiple trainings on autism, including a full-day conference last

March and two full-day trainings this past fall.

This issue of *The Sun* is meant to provide you with some practical information on mental health and autism so that you can both improve your own knowledge and help build awareness among the professionals with whom you and your family work. And while access to mental healthcare is critical for many individuals with autism, the same access is just as critical to many family members as well. The stress of caregiving can take its toll and lead to a host of stress-related conditions, such as substance abuse and depression. Research has shown significant stress levels among caregivers—including one study that showed that mothers of adolescents and adults with autism experienced chronic stress similar to combat soldiers.

Most caregivers derive a great sense of personal fulfillment from caring for their loved ones with autism, but those positive feelings don't always offset the stress that occurs. If you are a caregiver, please take the time to think about your own mental health. Look for resources in your community to reduce stress where possible, reach out to friends who can listen and help, and don't hesitate to give us a call if you are looking for community resources.



Teresa Avery
Executive Director

For the signs and symptoms of anxiety disorders, visit the National Institute of Mental Health website at <https://www.nimh.nih.gov/index.shtml>.

A service of Autism Delaware



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Q&A with a pediatric psychologist

Therapy for children struggling with anxiety

Sun contributor and parent Cory Gilden is researching human development and family studies as a graduate student at the University of Delaware's college of education and human development.

Psychological therapies are gaining popularity for children and youth who have autism spectrum disorder (ASD) and struggle with anxiety. To answer some questions that families may have about psychological therapies, Autism Delaware talked to pediatric psychologist Emily Bernabe, PhD, BCBA, who serves clients with ASD at the Division of Behavioral Health at Nemours/Alfred I. duPont Hospital for Children.

A popular psychological treatment for those with ASD is cognitive-behavioral therapy (CBT). Can you describe CBT and who would benefit from this type of therapy?

CBT is based on the idea that how we feel, think, and behave are related. CBT therapists support individuals with ASD in reducing challenging behaviors and improving a child's or adolescent's coping, adaptive, and social skills.

One thing we do not do with individuals with ASD in CBT is treat the ASD

itself. Instead, we use CBT (or behavioral therapy) to treat secondary concerns or issues that are often related to autism: anxiety, depression, stress, anger, obsessive and compulsive behaviors, bullying, disruptive behaviors, or social skills deficits. Behavioral therapy can also help build skills (such as self-care and toileting) and support with sleep and hygiene.

Can you give some examples of how CBT can be tailored for an individual with autism?

It is important to individualize CBT for each child or teen with ASD and modify the therapy accordingly. Adjustments can be made, such as adding visual cues or including more role-play in therapy sessions. A therapist can also modify CBT by taking into consideration a child's special interests and talents because they may improve motivation and attention. For example, if a child with ASD is interested in the weather, his or her emotions could be expressed as a weather report.

The therapist will also consider the language abilities of the child and any sensory sensitivities and behavioral rigidity because these are often associated difficulties seen in children with ASD.

What can families expect from their child's therapy?

Parents can expect a CBT therapist to use several commonly used strategies during therapy sessions. First, therapy often involves an educational component. The child learns about describing feelings, emotions, and the physical responses. Therapy also involves assisting the child or teen in modifying cognitive distortions, such as all-or-nothing thinking.

Additionally, the behavioral component to CBT involves teaching coping and problem-solving skills and supporting the child in participating in exposure-based strategies. Exposure-based strategies are mostly used to treat anxiety and expose the child to the feared situation or object.

The child can expect to have homework after each session

so he or she can practice the skills in the home, school, or community setting.

What role does the family play in treatment?

Families play an important role in CBT. During parent sessions, the parents and therapist discuss progress and strategies to support the child or youth with ASD.

It is also helpful for parents to learn about behavioral principles or strategies so they can use these techniques in the home and community setting.

Parents also support their child or teen by encouraging him or her to complete the homework assignments.

What is the initial appointment like?

At the first appointment, the therapist gathers information from the parents and child with ASD regarding their concerns. The therapist may ask the parent about the child's developmental history. If parents do not want to discuss the child's difficulties in front of him or her, they are encouraged to ask the therapist to meet in private.

Also during the first appointment, the therapist often spends time getting to know the child and building a rapport through games and other getting-to-know-you activities.

How would you recommend that parents prepare their child for his or her first appointment?

Parents can let the child know that he or she will not be getting a medical checkup or shots. Instead, the child will spend part of the first appointment answering some questions and another part of it playing with toys. Parents can tell their child that he or she is going to this appointment to talk about his or her own strengths and weaknesses.

Is CBT covered by insurance?

Insurance coverage of behavioral health treatment and psychological and psychiatric care has been required in Delaware since the enactment of Del. SB22. (For details, see *The Sun* [October–December 2012].) The child must have a medical diagnosis of autism from a physician or psychologist who determined that the care is medically necessary.

Parents are urged to double-check with their insurance company about coverage for psychological therapies.

Anxiety screen available

Mental Health America provides a brief anxiety screening at <http://www.mentalhealthamerica.net/mental-health-screen/anxiety>.

Explaining mental health and ASD Continued from p. 1

if needed, support and guidance from trained mental-health professionals. Family members and caretakers of individuals with ASD should be aware of the signs of anxiety (such as increased worrying, stomach aches, headaches, and fatigue) and depression (such as irritability, changes in sleep patterns, and increased isolation). Caretakers should also recognize that defiance and acting out may be ways of communicating frustration and unmet needs. Caretakers can begin to acknowledge and validate these feelings by helping to name them.

Finding activities that the individual enjoys and at which he or she excels is an excellent way to build self-esteem and confidence. Validating feelings and building coping skills through enjoyed activities are other ways that caretakers can support individuals with ASD who are dealing with mental-health concerns.

If symptoms of anxiety, depression, or behavioral difficulties continue, contacting a trained mental-health professional may be beneficial. These professionals can help families understand the overlap of ASD and mental-health diagnoses and can teach ways to intervene while supporting the person with ASD.

Trained mental-health professionals can also help teach caretakers ways to

- manage difficult behaviors,
- introduce and identify developmentally appropriate coping skills, and
- teach identification of emotions as well as regulation skills.

Remember, as a caretaker, the best thing you can do for someone with ASD is to provide a loving and supportive environment.

A review for Delaware’s providers

Young adults with ASD in behavioral and mental-health crises

Sun contributor Peter J. Doehring, PhD, is founder and director of ASD Roadmaps. In a paper presented to Delaware service providers last October, Doehring addressed the behavioral and mental-health crises that strike young adults on the autism spectrum. Here are the highlights.

Behavioral crises can include episodes of aggression or self-injury that are so severe that they put the health of the person with autism spectrum disorder (ASD) or others in immediate danger. The risk for these kinds of episodes generally increases in people with more significant developmental disabilities.

Mental-health crises can include bouts of depression that leave the person considering or attempting suicide.

These crises occur more often than you would expect. In a 2009 survey, young Pennsylvania adults on the spectrum and their parents reported that, in the previous year, behavioral and mental-health crises resulted in

- emergency room visits for about 12 percent of respondents,
- in-hospitalization for about 8 percent of respondents, and
- police contact for about 23 percent of respondents.

More broadly, the 2015 *National Autism Indicators Report* painted a stark picture of the quality of life for adults on the spectrum, especially for those in nonwhite families with low incomes.

When I directed an in-patient treatment program for adolescents with ASD and related conditions, I learned that many behavioral or mental-health crises could have been prevented without highly intensive or specialized involvement.

For example,

- less-specialized practitioners can make a big difference in the lives of young adults with ASD by helping them handle the problems magnified by their poor quality of life.
- sleep problems can worsen behavior, yet good sleep protocols are readily available.
- physical discomfort from dental pain or medication side effects sometimes plays a big role.
- a problem in accessing basic services and supports, like primary care and respite, makes everyone less effective.
- those stuck at home all day, because they cannot find work or the right day program, are clearly more vulnerable to crises.

Evidence-based practices can address aggression and self-injury in behavioral crises. Most of these involve a positive and preventive approach that begins by

- understanding why the behavior occurs and then implementing accommodations,
- teaching skills, and
- reinforcing existing positive behaviors, which achieves the same ends or prevents the need for negative behavior to occur.

Consider a young man who becomes aggressive to gain attention, especially when he is bored. We can prevent his aggression by responding when he tries to get our attention appropriately, teaching him new ways to get attention, and reducing the need for attention by adding activities to relieve his boredom.

According to the American Psychological Association, “evidence-based practice is the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences” (<http://www.apa.org/practice/resources/evidence>).

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An overview of anxiety

Sun contributor Susan Peterson, PhD, BCBA-D, is the clinical director at Autism Delaware™.

Anxiety disorders are frequently seen in people on the autism spectrum. The percentage of individuals on the spectrum who also have an anxiety disorder is estimated at 11–89 percent. Most likely, about 40 percent of the

autism population has a coexisting anxiety disorder (<https://www.iidc.indiana.edu/index.php?pagelid=anxiety-and-autism-spectrum-disorders>; Joshua Nadeau et al. "Treatment of comorbid anxiety and autism spectrum disorders." *Neuropsychiatry* 1 [6]: 567–8).

The types of anxiety disorder include specific phobias, social anxiety disorder, generalized anxiety disorder, and obsessive-compulsive disorder (OCD). Some of these anxiety disorders can be hard to diagnose, particularly in someone with limited verbal skills. For example, the stereotyped repetitive behavior, which is associated with ASD but not necessarily associated with any particular distress, may be confused with the obsessions and compulsions associated with OCD.

Medications are often used to treat anxiety disorders in neurotypical people. Unfortunately, limited data exists on the effectiveness of drugs used to treat anxiety in individuals with ASD.

Cognitive-behavioral therapy (CBT) is the most effective and established treatment for anxiety disorders but usually requires a high degree of verbal skills. For example, a person diagnosed with a phobia would work closely with a cognitive-behavioral therapist to define the details around a feared situation. (To alleviate the feared situation, the details are used in graduated exposure.) Obviously, this technique would be a challenge for someone with limited verbal skills.

Although a great deal of research on using CBT with individuals with ASD does not exist, there is evidence that individuals with higher levels of verbal skills can benefit from CBT. Parent involvement can also help; it may even make up for a child's limited verbal skills and allow the possibility of more effective treatment.

Young adults *Continued from p. 4*

There are fewer evidence-based practices for anxiety and depression, but many people find both behavioral and pharmacological interventions helpful. Adults on the autism spectrum are another valuable resource. (In Doehring's October workshop, self-advocates Reese Eskridge and Kyle Bryan offered compelling insights into what works for them. For more from Eskridge, see his article on this page, and for more from Bryan, see his article on page 7.)

Too often, people look for a magic bullet when the solution involves small steps done well and done consistently. (Stories about little, but important steps that Doehring took to make his daughter Margot's life better are available at <http://www.asdroadmap.org>.) These steps may not require a specialist in ASD, so they are too often overlooked. Each of these solutions may point to the need for system change that agencies, like Autism Delaware, advocate for.

What mental-health providers need to know about autism

For most of the long history of mental-health studies, few have accounted for autism and its complications. Only recently have mental-health organizations turned to significant information to create effective services, such as therapy, counseling, and interventions.

To further this process, the first thing a mental-health provider should do is build bridges with the autism community. The provider can learn fundamental essentials about autism by reading online blogs and personal stories in addition to official organizational and academic material.

As mental-health providers gain new knowledge, they will be better able to map out fundamental characteristics and develop an ability to pinpoint where each of the mental-health implications resides on the vast autism spectrum. In turn, they can establish common cases and trends for faster reference (at no expense to services).

For example, anxiety in people with autism most frequently resides within the context of relationships, perfectionism, and fear of the unknown. Knowing this is informative but could also result in no diagnosis for anxiety.

Next, mental-health providers must separate autism from mental-health disorders while remembering that they are interrelated. Co-occurring mental-health conditions (known as mental comorbidities) must be treated separately from autism symptoms, and providers working with people on the spectrum need to recognize patterns that lead to accurate diagnoses. Because patterns do not imply that all patients with autism are the same by nature, the best practice would be to use holistic, comprehensive assessment tools for evaluations and diagnostic procedures.

With this said, I believe the single best methodology that will help any individual on the autism spectrum is to commence studies on autism (and other intellectual and developmental disabilities) as soon as possible—and to always keep learning. Mental-health providers and their organizations would do well to collaborate with other professionals, too, because some focus more on autism than others do.

Mental-health providers must also welcome people with autism and their families warmly and make offices and treatment facilities family- and autism-friendly.

Finally, providers not only must use comprehensive, insightful, useful, and family-friendly information and services but also must stay in contact with the family until the service is completed and the individual with autism can better cope with his or her mental-health issues.

Sun contributor Reese Eskridge is a long-time self-advocate whose presentation was well-received at an autism conference in 2016. This article is an overview of that presentation.

Parental concerns about long-term care for their adult children



Danielle, Paul, Gerri, and Dwayne Olivieri

// If my wife and I died today," says parent Dwayne Olivieri about his greatest concerns regarding long-term care for his 30-year-old son Paul, "he'd be in a world of hurt."

Caregiving roles drastically change when children

with autism age out of school and lose the educational supports and services they received through the Individuals with Disabilities Education Act (IDEA). Olivieri calls it "the post-21 world, and it's a huge change for families. All of those support people just disappear." During this difficult transition, parents become so immersed in securing financial and other supports—as well as working full-time jobs and everyday caregiving—that they have no time to consider the most difficult and painful question of all: *Who is going to take care of my child when I can't?*

As Dwayne Olivieri and his wife Gerri approach the age of 56, they realize that they have to start looking into long-term housing and financing, most likely in a state-sponsored residential facility. They are also concerned about their daughter Danielle having to, one day, take on responsibility for Paul after she starts a family of her own—and their closest relatives live an hour away. The only community support they have is from Autism Delaware™ and its adult employment program, Productive Opportunities for Work and Recreation™ (or POW&R™, for short).



Monica and Rohan Patel

// What happens when I can't do this anymore?" asks parent Susan Patel. Arthritis and back issues compound the stress of caring for her 23-year-old son Rohan. "And what about the days when I don't feel like doing this but have to? If I'm sick and can't drive Rohan to his program, how does he get there?"

"I'm actually more stressed and harried now than when he was in school," continues Patel, "because

the day school stopped, the transportation stopped. The moms can't even get together now; we all have different drop-off times and places." Patel has to drive an hour each way to get Rohan to his work and volunteer assignments through POW&R.

Like the Olivieris, the Patels cannot rely on family to take on some of the responsibility for Rohan's long-term care. Plus, Susan Patel's parents recently moved closer to her, and while

both of her parents are healthy, she anticipates becoming her parents' caregiver as they age:

"There are a lot of people I know who are in this sandwich generation and taking care of their own parents."

Susan and her husband Tushar have given a lot of thought to Rohan's living situation and met with the Division of Developmental Disabilities Services (DDDS) and Housing and Urban Development (HUD). More than anything, the Patels want a smooth residential transition for Rohan: "It's really sad to think of the people who have lived with their parents for 50 or 60 years, and suddenly, they're thrust into a totally different situation. We don't want that for our son."

// The future is not with us," says parent Dale Oberender.

"We're not getting any younger." Both Oberender and his wife Barb know they need to start working more closely with DDDS regarding long-term care for their 22-year-old son Eric. "But one transition at a time," adds Barb. Eric recently transitioned out of school and into POW&R, where he works two jobs and enjoys a consistent schedule of volunteer activities.

When Barb worked full time, her job provided some time away from Eric's care. Now retired, Barb is fully involved and always on guard because Eric is nonverbal and relies on his parents to intuit his needs. "It puts a lot of stress on our mental health," notes Dale, "because we need to be aware of Eric all the time."

Eric's parents know that he is never going to be independent. The best-case scenario would be a group home for Eric. His parents hope to have initial oversight that will be transferred eventually to someone younger. "We want to do it while we're still around," continues Barb, "and hope some cousins will step in to help with the oversight and advocate for Eric."

For now, the Oberenders enjoy strong community support, and Dale reciprocates by serving on Autism Delaware's board of directors. He and Barb take time away when they can. For example, the several weeks of respite that summer camp offers "open up a whole new world for us," smiles Dale, "because we're not thinking the same way."

Of the many stressors experienced by parents, the long-term care of their children on the autism spectrum weighs heavy. Here, three families describe their concerns to *Sun* contributor Liz Carlisle.



Barb, Eric, and Dale Oberender

Benefits gained through mindfulness and meditation

Sun contributor Kyle Bryan is an Autism Delaware™ office assistant as well as an autism advocate.

In my youth, I learned outdoor survival skills and community social skills, which helped me think through the tasks at hand before acting on them. These skills were reinforced when I took classes in martial arts. I also acquired the skill to meditate and was able to calm my mind and body when there is outside pressure.

In the confusion of autism, obsessive-compulsive disorder (OCD), depression, and conversion disorder, I forgot these disciplines, but they were reintroduced to me recently by a colleague in the Autism Delaware office. While writing this

article, I remembered what I'd been taught in my youth. As a result, I was able to comprehend the valuable lessons taught by scouts and martial arts: the value of mindfulness and meditation in restoring balance within me.

I now see how the reinforcement of these lessons continues to aid in my mental, physical, and spiritual well-being. Mindfulness provides the opportunity to think before acting and speaking as well as consideration for other people's thoughts and beliefs. And breathing meditation provides the calm I need by clearing my consciousness of needless chatter, freeing my body of the energy drag and a high heart rate, and replenishing my oxygen supply. Together, mindfulness and meditation help me maintain an inner stability and provide me with the strength I need to succeed in the world.

The importance of finding a balance

Often, parenting a child with autism spectrum disorder (ASD) is a struggle to meet the child's needs. In this article, two parents share how they faced the increased stress and anxiety and created balance in their lives.

Sun contributor Gail Hecky, MEd, retired from a 35-year career in special education before joining the Autism Delaware staff in the Lewes office.

With her son Connor now employed through Autism Delaware's adult employment program, Lisa Caroff reflects on the many approaches she found useful through the years. Though perhaps not as clear at the beginning of her son's life, Caroff now realizes the importance of spending time away from the topic of autism to balance her own needs and her child's. She accomplishes this by planning an evening or two every week when she can do something for herself. She participates in a regular trivia game or goes out to dinner or a movie with friends. In addition, Caroff schedules exercise time and weekly sessions with a personal trainer. Her husband also benefits from planning regular time to exercise or go out with friends.

To find a balance between her needs and her child's in the past, Caroff found invaluable the respite services offered through the Sussex Consortium. Her family took full advantage of overnight camps once Connor became more independent. Caroff also found it beneficial to talk to objective professionals, such as psychologists and counselors—both alone and with her husband and son.

When Connor was enrolled in the Delaware Autism Program (DAP), Caroff took advantage of the many parent support groups offered through the consortium and Autism Delaware. These connections helped her learn about community resources and services and eased her feelings of isolation. She says she received tremendous benefit from meeting other parents. Caroff's involvement in Special Olympics generated another avenue for connecting to the parents of children with

special needs. The connection contributed much to Caroff's own personal growth and to accepting family life affected by autism spectrum disorder (ASD). The Caroff family continues to rely on the assortment of outlets that have helped them manage a life affected by ASD.

The most difficult time for Ron and Shelby Givens was the first two years after their son Cade (now 4 years old) was diagnosed with ASD, because appropriate services were hard to access—if available. Shelby found herself, typically an optimistic person, turning to antidepressants to cope with the anxiety and stress.

The Givenses eventually began meeting with state lawmakers and pressing for legislation that would adequately fund early intervention. They now find that the applied behavior analysis (ABA) offered to Cade by the Brandywine Autism Center in Milford has been a godsend, says Givens. She and Ron have regained a sense of hope and remain strong for one another.

Besides having a supportive partner, Shelby Givens places great importance on reaching out to peers. Her most important resource is online Facebook groups. At the top of her list is the Special Needs Moms Network (<https://www.facebook.com/groups/specialneedsmomsnetwork>; #snmoms network). Anxiety Warriors and They Don't Look Autistic are two other closed Facebook groups that offer parents a chance to share the details of their lives. Givens admits to experiencing great relief when she found other parents who understood and related similar circumstances. These days, a broad smile covers Givens's optimistic face.

All parents are encouraged to take advantage of respite services. For more information, call Autism Delaware.

PARENT PARENT Written by parents
for parents



Rob Gilsdorf

We all have witnessed that special kind of shock that comes along with accepting autism into our lives: The rapid heartbeat, adrenaline-fed fear that shakes our souls. The anger and disappointment are unavoidable; the acceptance and resulting dedication to serve and survive, welcomed once they arrive.

We embrace our new mantra: "God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."

As our energy and dedication turn into action and accomplishment, our children grow, learn, and thrive with our assistance. Each of my children is amazing, and my son on the autism spectrum is 26 now and continues to outpace our expectations. Our efforts have been arduous, yet the rewards never seem to end.

As we give our all to those we love, too often we neglect ourselves. In reflection, this seems a selfless act, focusing all our energies on helping our children and family manage the challenges we face, but it is a most dangerous thing. If we don't work diligently to take care of ourselves, we suffer, fall ill, and are unable to lend the vital support our family needs. The caregiver requires care!

The intent of my message is to urge you to take a different pathway than I did. Although I managed to develop a good professional career and to help my son and others in our community, along the way, I sidelined my personal well-being. I allowed myself to get rundown and slipped slowly into a danger zone of fear, anxiety, and depression. And I began drinking way too much alcohol. It was a gradual submission but a dangerous one. Eventually, I reached my low point.

I made it back from the edge of total despair, and bring this message to you out of concern for your personal journey. Please keep an eye out for yourself. You need care if you are to care for others. While this forum is not the place for me to share my story of silent suffering and amazing recovery, I am willing to share my personal story with you in strict confidence. If I may help, I am here to serve. Please give me a call. My phone number is (302) 378-5184.

—Rob Gilsdorf

How to vacation so it's relaxing

Vacationing with a child who has autism brings up many questions: *Should we drive somewhere? Should we fly? Should we stay at home and play in the backyard?* My family has done all three—and so can yours! Here are some ideas I've gleaned from vacationing with my son, Jake, who is on the autism spectrum:

Choose your destination.

Is there a beach? If yes, then start packing. *Does your child love Disney characters? How about rides?* Walt Disney World and Hersheypark both have special passes for visitors with a family member with a disability. But each is also different (as outlined on their websites).

Note: Passes make getting on rides easier for our kids, which in turn makes life easier on us.

Decide on how to travel.

Car rides seem easiest. My family has driven to the Outer Banks of North Carolina with Jake—an eight-hour trip! And he did better than I did. We always travel with his portable DVD player, we try to eat at the same time so we can anticipate when he'll be hungry, and we bring surprises for along the way. The surprises can be DVDs, sticker books, lollipops, or other special food treats.

Air travel is more difficult, but it can be done. I recommend using social stories to help your child "see" what the airport is like. You could even take a practice visit, going as far as the security line. When you are actually going through security, don't be afraid to ask for help from a TSA (Transportation Security Administration) agent. If the line isn't moving and your child needs to move on, the TSA agent can take you to the front, ahead of other travelers.

We call the airline and ask for bulkhead seating. These seats have a wall in front of them (instead of more seats) so your child can't kick anyone. You won't have under-seat storage, but it's a small price to pay.

Note: If the airline personnel tell you the seats are for travelers with disabilities, remind them that autism is a disability according to the federal government.

Jake carries his backpack onto the plane, filled with his DVDs and player, gum, books, food, and water bought in the airport plus his security blankets. The backpack on his lap also serves as a pillow of sorts when he leans forward.

Luckily, I've found, most people are very understanding and some have been helpful during my family's traveling experiences.



Frankie and Jake Nardo on the island of St. Martin

Continued on p. 9

PARENT PARENT

How to vacation

Continued from p. 8

I have heard about other parents who make goody bags for the people seated around them and the flight attendants as well as for their children with autism. The bags contain a small card explaining autism plus some candy and, maybe, some earplugs.

Relax.

When planning your vacation, it's important to remember that your child will react to situations on vacation just like he does at home.

Will there be fireworks? Then, bring a headset or earplugs.

Does your child love pools yet tend to stand in one spot or flap a lot at the water? So what! Let him enjoy things the way he enjoys them, and don't get too hung up on what other people are thinking.

We parents need to let the stress level drop and have fun, too. Take turns with your spouse to enjoy some alone time or with your other child(ren).

Is babysitting available? We've used sitters at Disney World, and it was like grandma came over to play. My husband and I had a nice dinner alone, too.

Don't be afraid; a vacation can be relaxing—and it will be fun!

—Jen Nardo

April–June 2017

Autism Delaware programs

April

1—Sensory friendly movie: *The Boss Baby*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

2—Spring bunny train ride. Wilmington & Western Railroad. 2:30PM. *Register:* Kris Grant at (302) 224-6020.

4, 18, 25—Lego club. Autism Delaware Newark office. 6:00–6:45PM and 7:00–8:00PM. *Register:* Heidi Mizell at (302) 224-6020.

5—Parent coffee hour. Hampton Inn. Middletown. 9:30AM. *RSVP:* Jennifer Sparks at sparkjm@aol.com.

5, 12, 19, 26—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. *Register:* Karen.Tuohy@redclay.k12.de.us.

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

15—Sensory friendly movies:

- *The Boss Baby*. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.
- *Smurfs 3: The Lost Village*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

17—Grandparents support group. Autism Delaware Newark office. 6:30–7:30PM. *RSVP:* Heidi Mizell at (302) 224-6020.

May

2, 9, 16—Lego club. Autism Delaware Newark office. 6:00–6:45PM and 7:00–8:00PM. *Register:* Heidi Mizell at (302) 224-6020.

May Continued

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

10—Parent coffee hour. Panera Bread. Wilmington. 7:00PM. *RSVP:* Heidi Mizell at (302) 224-6020.

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

20—Sensory friendly movies:

- TBD. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.
- *The Nut Job 2*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

June

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

7—Parent coffee hour. Hampton Inn. Middletown. 9:30AM. *RSVP:* Jennifer Sparks at sparkjm@aol.com.

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

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

17—Sensory friendly movies:

- TBD. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.
- *Cars*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

19—Grandparents support group. Autism Delaware Newark office. 6:30–7:30PM. *RSVP:* Heidi Mizell at (302) 224-6020.

For an up-to-date list of Autism Delaware programs, visit autismdelaware.org.

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

INSIDE Autism™ Delaware



Four-time scholarship winner accepted into graduate school

David Lee Cook, Jr., admits that his transition from high school to college was difficult to handle, but in taking advantage of the resources available to him at

West Chester University, he adjusted well to college life—so well, in fact, that Cook is now matriculated in the university’s graduate degree program for applied sciences. And for his effort, Cook was awarded a fourth Autism Delaware Adults with Autism Scholarship.

Bringing out the celebrities

Every spring, almost 300 sports and broadcast celebrities and sponsors enjoy the premier golf tournament in Delaware. This year, the 16th Annual Drive for Autism Celebrity-Am Golf Outing, presented by Smithfield Foods, takes place Thursday, June 1.



Darrell Waltrip and Artie Kempner at 2016 golf event

Coinciding with the AAA 400 Drive for Autism at Dover Downs, the golf outing has more than 25 NASCAR drivers scheduled to play: Cup Champions Jeff Gordon, Jimmie Johnson, Darrell Waltrip, Kevin Harvick, Matt Kenseth, plus Danica Patrick, Austin Dillon, and Xfinity champs Ricky Stenhouse, Erik Jones, and Ty Dillon. The racing contingent will be joined by stars from the NFL, NHL, Major League Baseball, as well as Olympic gold medalists and broadcast icons from Fox Sports, CBS Sports, and ESPN.

“Many of our celebrities have personal connections to autism,” notes Drive for Autism chair Artie Kempner, “but even those who don’t have personal connections make the outing an every-year event on their schedules because they want to raise funds in support of Autism Delaware programs and services.”

For more information, visit autismdelaware.org.

Learning personal skills as well as golf techniques

Do you know where your child on the spectrum can learn personal skills as well as good sporting technique?

At Autism Delaware’s junior golf program. In addition to teaching golf techniques, professional golfer and coach Butch Holtzclaw helps students craft their personal skills, such as good sportsmanship and perseverance.

Autism Delaware’s junior golf program is designed for youth aged 8–21. Taking place at The Rookery South Golf Course in Milton, the program runs for five weeks, usually with alternating days of instruction and a choice of times.



For more information, visit autismdelaware.org. Or call (302) 644-3410, and ask for Autism Delaware program and operational assistant Gail Hecky.

Day camp available

In August, 30 campers will enjoy summer day camp at the Children’s Beach House in Lewes.

Designed for youth entering third grade and up (through and including age 17) during the 2017–18 school year, the campers enjoy ample opportunity to swim, kayak, sail, and take part in arts and crafts and a low-ropes course. All these activities focus on building self-esteem and enhancing communication and socialization skills.

This annual program applies the challenge-by-choice approach: Children are encouraged—but never forced—to try new activities.

For more information, visit autismdelaware.org. Or call Autism Delaware family service coordinator Dafne Carnright at (302) 644-3410.



Meet Autism Delaware's newest team member

Annalisa Ekbladh is Autism Delaware's new family support program manager. Ekbladh assumed day-to-day management of the family support department on January 9.

Ekbladh has worked with children and families in both the public sector and the nonprofit community. "Two of Annalisa's former roles—as the Center for Disabilities Studies' program manager and the Christina Educational Enrichment Fund's executive director—demanded skills and knowledge that are ideally matched for the work Autism Delaware does today as well as the work to be done in the future," notes Autism Delaware associate executive director Brian Hall.

"Over the past decade," adds Ekbladh, "I have had the opportunity to work together with Autism Delaware on many different levels. My first experience with Autism Delaware was as a parent looking for help to identify supports for my son as he moved back into the public schools.



"I have a profound respect for Autism Delaware's mission," continues Ekbladh, "and am thrilled to be able to work with the committed family support staff in serving families in Delaware. I look forward to meeting and working with our amazing Delaware families as we expand our family support programs and services."

For a complete list of Autism Delaware staff, visit autismdelaware.org/about-us/staff.

A glowing report

On December 1, 2016, a glowing report on Autism Delaware's adult employment program was issued by two experts:

- Teresa Grossi, PhD, of the Indiana Institute on Disability and Community at Indiana University, and
- George Tilson, EdD, of Tilson and Diaz Solutions, Inc.

Their summary of the program—called Productive Opportunities for Work & Recreation™ (or POW&R™, for short)—follows:

"POW&R is a unique organization that is rooted in strong values and principles for serving individuals on the autism spectrum. Strong family partnerships, a cohesive and talented leadership team, and a committed, dedicated, and loyal staff—essential elements that are key for POW&R to continue to be a lead provider in Delaware as well as nationally. POW&R has addressed a number of operational and service delivery issues over the years that many provider organizations are just now considering.... Many organizations can learn from POW&R."

Holiday giving



The startup to the 2016 holiday season began just after Thanksgiving with a statewide collection for the Food Bank of Delaware. In the Lewes office, Autism Delaware direct support professionals Iya Jones and Michelle Robbins gathered food with adult employment participant Rose Campbell and delivered the donation on December 15. On December 21, the Newark office delivered its 118-pound donation to the Food Bank. Assisting with the gathering and delivery were (at left) Autism Delaware staff members Liz Carlisle, Kyle Bryan, Deanna Principe, and Margie Rowles.

Autism Delaware also joined forces with Hertrich Toyota of Milford to make a success of this year's Toys for Tots drive.

Among the donations were sensory friendly toys suitable for children on the autism spectrum. At right are Hertrich Toyota sales associates Bill Vernon and Rebecca Jack, general manager Tushar Patel, used car manager Scott Robinson, and sales associate Jordan Starke, as well as Autism Delaware adult employment participant Eric Oberender, direct support professional Luiz Valdez, and program and operational assistant Gail Hecky.





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Helping People and Families Affected by Autism



Autism Delaware partners with AAA Mid-Atlantic and Dover International Speedway!

The Monster Energy NASCAR Cup Series race takes place June 4 at Dover International Speedway—and volunteers are needed to make a success of this event.

Want to get involved?

Send an email of interest to Autism Delaware's events manager, Deanna Principe:

deanna.principe@delautism.org

AutismDelaware.org