Also in 1998

What was happening when the seeds of Autism Delaware were sown?

In this issue of *The Sun*, each contributor to the Autism Delaware story shares a coinciding piece of history.

Here's one from the editorial staff to start:

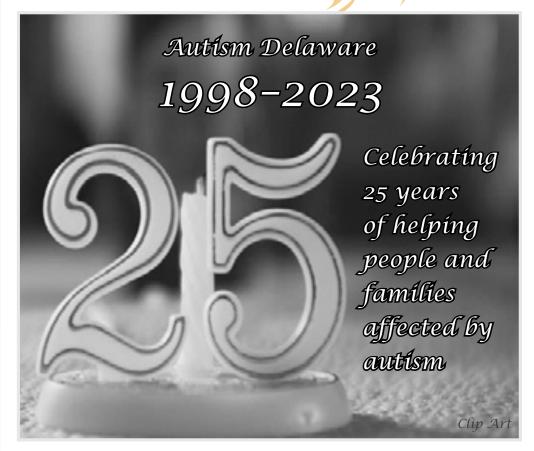
Andrew Wakefield and his colleagues published their paper in *The Lancet* suggesting that the measles-mumpsrubella (MMR) vaccine triggers autism. The theory was debunked by comprehensive epidemiological studies and eventually retracted (doi: 10.4103/0019-5545.82529).



Our mission

To help people and families affected by autism





overed in this issue of *The Sun* is the story of Autism Delaware from its homegrown beginning in 1998 to its current rebranding effort:

- An Autism Delaware founder, Marcy Kempner organizes and advocates for adult services with a small group of parents—p. 4–5
- Past Autism Delaware executive director Theda Ellis adds her skills and experience to help create services across the state and throughout the individual's lifespan—p. 6–7
- Theda's successor, Teresa Avery, supports staff as the agency faces an ever-growing autism community—p. 8–9
- Autism Delaware marketing and communications manager Lisa Walenceus conducts the agency's current rebranding effort—p. 10







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If you want to be removed from The Sun's mailing list, please call or mail a request to the **Newark office (noted above)** or email your request to Carla. Koss@autismdelaware.org.

Autism DelawareSM, Productive Opportunities for Work and RecreationSM and POW&RSM, Parent to ParentSM, and Autism Care TeamSM and ACTSM are service marks of Autism Delaware Inc.

Gratitude, appreciation, and optimism

y the time you read this letter, I will have completed my term as president of the Autism Delaware Board of Directors, Several themes come to mind as I reflect on my experience over the past three years. Of course, I feel gratitude for the opportunity to serve the autism community, but I also appreciate the way the Autism Delaware board members and staff responded to COVID-19's unprecedented challenges.

For example, COVID reduced our ability to provide some services when a number of our community partners had to suspend or terminate their relationship with us. In turn, work opportunities were lost for a number of participants in our adult employment program. And this loss not only upended lives, but it also reduced our revenue stream to the point that we had to cut back on the range of community services we could offer.

COVID also limited our fundraising ability. Fewer celebrities attended the 2022 Drive for Autism, so our annual golf fundraiser diminished in size and yield. Additionally, we were forced to cancel the 2022 Blue Jean Ball because of a lack of sponsors. To overcome these disappointments, the Autism Delaware team is looking for and developing new ways to raise the funds that will sustain much-needed programs and services.

Another effect of COVID: staffing challenges. Attracting quality employees and retaining them have become more and more difficult. To address these issues, we've raised the wage scale and offered hiring and retention bonuses The staff has also stepped up recruiting efforts.

All of this effort makes me feel optimistic as we begin



Brendan O'Neill Past President Board of Directors

celebration of Autism Delaware's 25th anniversary in 2023. Looking past the challenges we've been facing, I see the faces of the staff and volunteers who continue to find ways around the challenges. In my judgment, these folks make Autism Delaware's future look bright.

We are fortunate to have an excellent leadership team. Led by Autism Delaware's executive director, Brian Hall, the agency has been kept on track by Brian's focus on our strengths. His future plans include adding an applied behavioral analysis (ABA) program to Autism Delaware's list of programs and services. Not only will ABA provide our community with an additional service, but it should become a profitable endeavor. Autism Delaware remains on solid financial ground because our revenues match up with our operating expenses.

Also, Autism Delaware's family support services continue to grow. After acquiring the tools, virtual family services were available without interruption to established clients as well as to new

Continued on p. 12

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.



The Sun rises

In November 1998, the first bimonthly issue of The Sun was created in a word-processing program and distributed by placing a copy in each Delaware Autism Program (DAP) student's backpack to take home to their parents. In addition to introducing the recently established Autism Society of Delaware on the first page (pictured at right), the next three pages included a list of upcoming events, an overview of the committees that were formed to follow the work, a few relevant news items, and an ad asking for testimonials about treatments or therapies that either worked or didn't.

Twenty-five years later, The Sun is a 12-page, two-color, interactive publication that's desktop published quarterly and distrib-

uted electronically. As a leading resource for expertise and advocacy, each issue highlights a topic of relevance to the autism community, and the articles range from best practice or the work of experts in their fields to the personal stories of individuals with autism or their parents or caregivers. Lots of resources are also included.

The Sun mailing list has gradually expanded to include all First State schools enrolling students with autism as well as DAP schools. The distribution list also includes past contributors to the newsletter and anyone requesting to be added to the list, plus Delaware's elected officials, including the governor, lieutenant governor, and all Delaware General Assembly legislators.



Tell your story

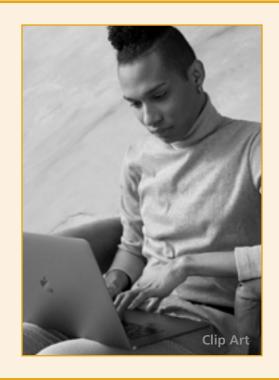
Are you an autistic with a story to tell?

The Sun is asking individuals with autism to share their unique perspectives with our readers.

Not only will others with autism find it reassuring to learn that someone else is facing a similar challenge, but they will also appreciate reading about how you addressed this challenge and the result.

Feel free to include the tried-and-failed options and why they failed as well as the options that succeeded and why.

Type your story in 300 words or less, and email it with a high-res photo to Carla.Koss@autismdelaware.org. Carla will respond with an overview of the publication process and send a typeset page for your final approval.





n the spring of 1998, my son, Ethan, had just turned three years old, was a few months into his first year at the **Delaware Autism Program** (DAP), and I was less than a year into trying to wrap my head around his diagnosis and this scary new world my family and I were plunged into.

Ethan's teachers sent a flyer home in his backpack, asking anyone interested in helping to start a chapter of the Autism Society of America (ASA) to come to a meeting. Frances Ratner, another parent, was organizing the effort.

I had started getting involved in some DAP committees, and as I connected

more and more with other

parents, it became obvious that, while the school was great in many ways, a big world existed outside of it—and the landscape didn't look good for children like Ethan: General awareness of autism was scarce and full of disinformation. Treatments were often unproven and risky. And advocacy beyond school issues didn't exist.

At the first meeting to organize an ASA chapter in Delaware, I knew the effort was going to lead to something important. I was in!

Over the next few years, we started learning and building and making mistakes and going back to the drawing board to learn and build some more. The process was chaotic at times and frequently felt overwhelming. We were a small group of volunteers, holding

meetings, creating a newsletter, and doing our best to raise public awareness and to advocate, all while parenting one or more children with autism. Passions ran high, so disagreements were inevitable. So much was at stake for all our families.

Tremendously dedicated and talented people contributed in many different ways to our effort. But eventually we realized that to really keep going and to truly make a long-term difference, we needed help.

We had started having some success raising money and even managed to secure some grant funding. Both were big efforts in and of themselves, beyond the effort to maintain programs, projects, and initiatives. We used this Continued on p. 5



Marcy Kempner is a freelance sports television producer-director (and longtime Federer fan). She is also an Autism DelawaresM founder and longtime volunteer and board member as well as the parent of two neurotypical sons and one with autism.





A small group of thoughtful, committed citizens Continued from p. 4

money to start the process of hiring an executive director.

We struck gold in our first attempt. Theda Ellis not only had a wealth of experience in the world of disability services and systems, but she also saw the unmet need in our community and was at a place in her career where she could accept the challenge of building something meaningful and strong from the ground up.

Importantly, Theda was undaunted by all the craziness that came with her initial workspace—in my home, which included sharing the dial-up internet with my other school-aged children. Those were the days!

As a first step, Theda took on the difficult task of sorting through the hodgepodge effort made by our small group of volunteers and creating workable systems. Within two years, we had real office space and two additional part-time staff.

At this point, we were establishing ourselves statewide and sharing information, supporting families, and initiating advocacy efforts in a way that hadn't been possible in the past. And in 2007, we took our biggest leap to date by establishing our adult service agency that we named Productive Opportunities for Work and RecreationSM, or POW&RSM, for short. (See the box at right for more about POW&R.)

Today, Autism Delaware provides these services along with many other initiatives and supports for individuals with autism and their families throughout the lifespan.

It has been quite a journey from such small beginnings 25 years ago. As Margaret Mead put it so well, "Never doubt that a small group of thoughtful, committed citizens can change the world: Indeed, it's the only thing that ever has."

Autism Delaware's adult employment & community resources

Called Productive Opportunities for Work and Recreation (or POW&R, for short), Autism Delaware's adult employment program is nationally recognized for its focus on the needs, interests, and outcomes of the



individual with autism. To achieve this focus, POW&R staff members create networks that connect the individuals to resources that support their choices for how they live, work, and play in the community.

Local organizations, agencies, and businesses support POW&R by offering jobs and volunteer opportunities to individuals with autism. As a POW&R community partner, you can be assured of diversity in your workforce and customer satisfaction because POW&R staff will

- match your needs with the employee's skills.
- train the employee so he or she does the job the way you want it done.
- provide ongoing supports for quality assurance.

Become a POW&R community partner today. Call (302) 224-6020, ext. 202. Or send an email of interest to Katina.Demetriou@ autismdelaware.org.



Also in 1998

Sixteen-year-old tennis player Roger Federer played his first ATP Tour event. He earned 27 ATP Masters 1000 titles before retiring in 2022 as well as 103 men's singles titles and 20 Grand Slam event titles.







n 1998, a group of parents operating out of a New Castle County living room wanted to create an agency that could help people and families affected by autism across Delaware. They had managed some success and wanted direction for achieving more.

Having worked in the disabilities field for a number of years, I was open to using my skills and experience to once again create something new and different:

In Alaska, my position had served as the liaison to the state's sheltered workshops and rehabilitation programs. I had also written and managed Alaska's Centers for Independent Living Program and the state's Supported Employment Program. At the time, both were new services nationally. With no structure in place, both programs were starting from scratch. And for the supported employment project, the focus was on changing the stereotype concerning people with developmental disabilities (DD) as well as changing vocational services to meet their needs.

In Illinois, I had served on the team that developed a statewide strategic plan for the Illinois Department of Rehabilitation Services and also oversaw the statewide assistive technology (AT) initiative. At that time, research was showing that AT could make a significant difference in the lives of individuals with disabilities.

And in Delaware, I had served as the associate director and acting director for the University of Delaware's new university affiliated program (UAP), which is known today as the Center for Disabilities Studies (the Center). My work required some research, academic teaching, and grant development, plus the start of a statewide training program for the staff of community programs for people with DD.

My work also required much more writing than I had time for, so I opted to reassign this piece to adequately meet the UAP's federal grant criteria for disseminating information. The university pointed me to Carla Koss. At our initial meeting, she explained the publication process for the newspaper

In 2010, I hired Carla to do for Autism Delaware's The Sun what she'd done for delAware, and she continues the work today. format I wanted, suggested the name delAware, and offered to answer any future questions I might have. Realizing that Carla and I would work well together, I contracted her writing



and editing services. For the next nine years, we published an award-winning newspaper.

hen the group of New Castle County parents explained what they wanted in an autism agency, it seemed like the perfect opportunity to use what I had learned in the previous programs I'd been a part of: supported employment, independent living, strategic planning, and implementing statewide services. The real effort was in moving from a

background as a generalist in disability services to the more specific field of autism.

Continued on p. 7



Retired Autism DelawareSM executive director Theda Ellis, MEd, MBA, is an avid reader and enjoys traveling with her husband Warren. The couple resides in Arizona.





Helping to create a statewide autism agency Continued from p. 6

This effort began by developing a set of questions to ask our families: "How did the community see the organization?" "What are its strengths?" And "What was the need in the autism community?" Then, I interviewed all the board members and the most active volunteers as well as the people who were displeased with the organization's direction.

From their input, I learned that

- the state's educational program (called the Delaware Autism Program, or DAP, for short) was pretty good and the bus came on time.
- some families had access to respite care.
- their children learned and grew.

But the biggest response was a question to me: What's going to happen when my child turns 21 and ages out of the state's educational program?

These parents were looking to the future! And the one word they used over and over was "productive." Almost every parent said something along the lines of *My child has benefited from school and services*. *My goal for him or her is to be productive*. *I want my child to be able to work*.

These parents were also clear that they wanted something a little different than was generally available. What in particular, they weren't sure. Neither was I, but their goal sounded like the supported employment and supported living programs I had managed in Alaska and Illinois.

he next step was possible thanks to Marianne Smith, the director of the Delaware Division of Developmental Disabilities Services at the time. After listening to the New Castle County parents' stories, Marianne awarded us \$25,000 to conduct a study of best practices for adults with autism; however, a review of academic literature quickly

Having worked well with Susan, I hired her in 2012 to provide our Autism Delaware families with clinical services as well as behavioral evaluations. revealed that very little research had been published. We needed an informal study; I turned to former Center director Donald L. Peters, PhD, who helped design the study.

We then conducted an extensive telephone survey followed by personal visits to a variety of adult programs across the country. Having hired DAP psychologist Susan Peterson, PhD, BCBA-D,

Also in 1998 The New York Times nonfiction best seller list for the week of January 4, 1998: Midnight in the Garden of Good Citizen Soldiers. and Evil, by John Berendt by Stephen E. Ambrose #2 Angela's Ashes, The Dark Side of Camelot, by Seymour M. Hersh by Frank McCourt #3 The Perfect Storm, #8 Dirty Jokes and Beer, by Sebastian Junger by Drew Carey Into Thin Air, by Jon Krakauer Tuesdays with Morrie, by Mitch Albom The Man Who Listens to Horses, #10 Diana: Her True Story—In Her by Monty Roberts Own Words, by Andrew Morton Clip Art

to guide our research, we considered the most effective programs. We published our findings in a paper entitled *Research Brief on Adult Services with Autism,* which became the basis for our adult employment program.

he next step: develop a business plan and look for funding for the adult employment program. The New Castle County parents, having incorporated as the Autism Society of Delaware in 1998, had been saving money for the day that we could start supporting adults with autism. Knowing we would be subsidizing adult employment services for a number of years, we negotiated with the State of Delaware and received approval to start services. We then proceeded to hire a director. And in 2008, we began supporting two individuals and transitioning another four who were still in school.

Known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short), our adult employment program now offers day habilitation, social and wellness activities, and personalized supportive living services as well as

Thank you, the Bashkow and Nagowski families, for taking a chance with your precious children and letting them be the first POW&R participants.

adult employment—and is a nationally recognized program.

Within the next 10 years, the Autism Society of Delaware became an independent 501(c)(3) nonprofit, merged with the Lower Delaware Autism Foundation, and changed our name to Autism DelawareSM. With a range of programs and services, we were now better able to serve our ever-growing community across the state and across the spectrum.

n 2010, I'd recently completed my master's degree in business and was eager to put my education to work on behalf of a crucial community mission. I applied to Autism DelawareSM because its mission is to help people and families affected by autism. Executive director Theda Ellis hired me for my business and communication skills and despite my lack of experience in fundraising and managing a nonprofit organization. To get that experience, Theda put me immediately to work recruiting sponsors for Autism Delaware's annual auction.

Of course, I felt I would be functioning on shaky ground, but Autism Delaware's board offered incredible support. The board's members called to check on me, to offer help and advice—and to

talk me through some pretty big mistakes!

By 2012, I could see the direction that Theda and her board of directors were headed and how to get there: strive to meet the growing needs of the autism community across their lifespans as well as across the state. As Theda stepped away from the work and toward a well-deserved retirement, I officially became Autism Delaware's executive director.

Growth was the order of the day because the numbers seemed to be growing exponentially. More and more children were being diagnosed with autism, so both the children and

To function smoothly and support the work by Teresa J. Avery, MBA Clip Art

their families needed a range of support. Plus, more students with autism were graduating into adult services, so they needed the range of support offered by Autism Delaware's nationally recognized adult employment program.

To make all this happen, though, required more personnel, volunteers, funding, and advocacy than we could muster at the time. So, we collaborated as much as we could with whoever we could: state agencies and legislators, service and advocacy organizations, experts from other states, and the University of Delaware. Basically, we reached out to anyone who was able and willing to help us move our mission forward.

Let me make one thing clear: Autism Delaware's triumphs as a

result of this outreach were the result of the blood, sweat, and tears shed by Autism Delaware staff, board members, community partners, and volunteers. My job was to keep our agency functioning as smoothly as possible and to support the many talented and capable people who were doing the work and creating the impact.

It wasn't easy for them, as I would hear in their frustrations at times, but it was critical. And for this reason, they kept going. Continued on p. 9



Teresa J. Avery, MBA, is the managing director of the Executive MBA at Penn State's Smeal College of Business. An avid reader and horsewoman with a degree in equine science, Teresa resides with her husband Geoffrey in Chadds Ford, Penn.





To function smoothly and support the work Continued from p. 8

For example, when Autism DelawareSM public policy and community outreach director Alex Eldreth passed away suddenly at the end of 2017, his grassroots group of staff and volunteers pushed forward without him. Thanks to his early leadership and the community's continued effort, the Alex Eldreth Autism Education Act was signed in September 2018.

As executive director, I was also exceedingly fortunate to have Brian Hall as my associate executive director. Today, I am proud to see how Brian is leading Autism Delaware toward even greater impact throughout the state. His expertise and focus on services will go a long way toward helping people and families affected by autism.

Granted, the needs are never small, but for 25 years, Autism Delaware has worked to acknowledge, define, and meet the varied needs of our families and their children. And with continued help from the community, Autism Delaware will continue this work for many decades to come.

Also in 1998

Real Quiet did not look or act like a champion thoroughbred when. as a yearling with crooked knees, he sold for only \$17,000. But two years later in 1998, **Real Quiet** won the Kentucky



Derby and went on to win the Preakness—losing the Belmont Stakes by the smallest margin ever! The 'ugly duckling who turned into a swan" lost out on horse racing's Triple Crown by only four inches.

Autism Delaware's family support services

- Family navigation—One-on-one support around a specific question or a challenge navigating the education or medical system is provided to families in both the English- and Spanish-speaking communities.
- Autism Care Team[™] (ACT[™]) program—Family support providers (FSPs)—who are also the parents of children with autism—offer one-on-one support on an ongoing basis.
- Parent education & support forums
 - family-networking dinners
 - virtual support groups
 - speaker series
 - parent to parent series
 - grandparent support groups
 - coffee hours
- Social recreation for youth and young adults
 - junior golf
 - sensory friendly bowling and roller skating
 - bounce nights & train rides
 - annual beach picnic, holiday parties
 - Blue Rocks games







INSIDE Autism® Delaware

he year 2023 marks Autism Delaware's 25th anniversary, and it will be a time to celebrate both the achievements of the autism community and our organization's milestones and accomplishments. As we look back on how far we've come, we will also look forward to our future growth and development with a renewed dedication to serving the needs of all autistic people who live in Delaware.

Our commitment to remaining on the forefront of autism advocacy and service required us to engage in deep reflection on our brand as a fundamental symbol of the work we do at this turning point in our organization's history. The result of this reflection is a significant change in our brand, including a new logo that reflects the hope and new horizon for the autism journey in the 21st century.

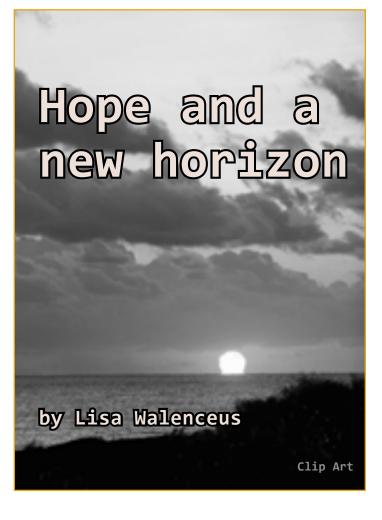
Our brand changes also mean we will no longer use the puzzle piece as part of our visual identity. This decision was a difficult one because, for so many people in our organization and in the wider community, the puzzle piece symbolizes their long and difficult struggle to gain recognition and inclusion for their loved ones on the spectrum. While we respect their experience and interpretation of the autism struggle, we also recognize that, since the puzzle

piece was first used in 1963, it has become a distressing symbol of ableism for many people on the spectrum.

In some minds, the choice of a symbol for autism is an either-or proposition: either the puzzle piece or the infinity sign preferred by many of today's advocates. At Autism Delaware, we have chosen a new symbol that represents the path forward to a world we want to help create—a world where each individual on the spectrum is welcomed and valued as an integral part of their communities.

We look forward to sharing our new logo with you during our 25th anniversary celebration.

All questions or comments are welcome and should be sent to me at <u>Lisa.Walenceus@autismdelaware.org</u>.



Ableism is discrimination or prejudice against individuals with disabilities (https://www.merriam-webster.com/dictionary/ableism).



For the past five years, *The Sun* has honored the language preferred by each person being interviewed and each contributor to the publication—whether they used identity-first language or person-first language.

In addition to continuing this policy, we have begun mixing the usage throughout our text as well as in Autism Delaware's media campaigns and print and digital publications.

As Autism Delaware's manager of marketing and communications, Lisa Walenceus is currently conducting the agency's rebranding and media campaigns as well as updating print and digital publications and the website.





o every participant and team who joined the festivities at the 2022 Walk for Autism—to everyone who fundraised to support Autism Delaware programs and services—to every volunteeer who supported the event so more fundraising dollars could be allocated to programs and services—and to the many businesses, organizations, and individuals who sponsored the twoleg event in Delaware City and Milton—many, many, many thanks! Your effort will go a long way toward helping people and families affected by autism.

Presenting sponsor



T-shirt sponsor

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Celebration sponsors

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Clean Delaware Inc.

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Kaleidoscope ABA Therapy Services

John F. Kleinstuber & Associates, Inc.

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McAndrews Law Offices

Pediatric & Adolescent Center

Porter Automotive Group

Pyramid Educational Consultants, LLC

State Farm

Jeanine O'Donnell Agency

Swiatowicz Dental Associates

J.W. Tull Contracting Services

Fundraisers

Top Delaware City fundraisers

#1 Team Cash



Tony's Team Team Ethan 2022 **Puzzle Masters** The Little Colonials

Top Milton fundraisers

#1 Ethan's Dream Team



Aven's Journey **Masons Team NeurodiversiTEAM** Diamond State Dentistry





Gratitude, appreciation, and optimism Continued from p. 2

contacts and referrals. COVID safety protocols may have required us to shut down some family-favorite activities, but our family support providers (FSPs) continue to offer much-needed one-on-one support.

Furthermore, Autism Delaware's adult employment program continues to turn a profit. Called Productive Opportunities for Work and RecreationSM (or POW&RSM, for short), this Autism Delaware program is much sought after by our community of young adults. When this nationally recog-

nized program can attract and retain more community partners and qualified direct support professionals (DSPs), more young adults will be able to take part in dayhabilitation, social and wellness activities. and community-based vocational services.

Recent achievements in advocacy help to make me feel optimistic, too. In 2022, Autism Delaware advocated successfully for the passage into

law of the McNesby Act. With this passage, an increase in state funding provides higher wages for POW&R's DSPs.

In summary, Autism Delaware is doing well as we begin our 25th anniversary year. In my experience, every person in the organization has worked through COVID challenges to achieve Autism Delaware's mission: helping people and families affected by autism. It has been my privilege to work beside Autism Delaware's dedicated board members, an excellent leadership team, and committed staffers. In fact, the ongoing commitment of the talented Autism Delaware staff was a joy to witness and to experience. For that, I am grateful as well.

For information on becoming an Autism Delaware community partner, send an email of interest to Katina.Demetriou@ autismdelaware.org.

> Want to apply to become a highly trained and respected **Autism Dela**ware DSP?

Click here!



INSIDE Autism[®] Delaware

Dafne Carnright promoted to director of family support services

Dafne Carnright, LPCMH, BCBA, CFPS, was promoted in September to the position of director of Autism Delaware's family support services having served as the interim director for the past year.

Dafne had volunteered at Autism Delaware before joining the staff as the new downstate coordinator in 2009. Since that time, she has been instrumental in the agency's growth, especially in the



central and southern parts of the state. In this capacity, she provided family navigation services, supported recreational programs, and advocated for legislative and systems changes.

In 2018, Dafne added her skills and knowledge to the design and development of the Autism Care TeamSM (ACTSM) pilot program. For her effort, she was promoted in 2019 to the position of manager of Autism Delaware's family support services. In this capacity, she supported ACT program staff and provided training and supervision to the program's family navigators and family support providers (FSPs).

Dafne and her husband Jeff are the parents of "an amazing young man on the spectrum, and our experiences drive my passion to support the agency and our community," explains Dafne.

"I have had the pleasure of seeing our agency grow over the years, from opening our first downstate office to the merger with the Lower Delaware Autism Foundation to adding new programs

and staff.

"As director of Autism Delaware family support services," adds Dafne, "I'm privileged to continue supporting such an amazing and passionate team and excited to continue serving the agency and community in this capacity."

Autism Delaware Family Support Services

referrals@autismdelaware.org (302) 224-6020, ext. 219