Autism Delaware 1998–2023

The Sun's yearlong overview of Autism Delaware's 25-year history continues in this issue with accounts from Brian Hall, Artie Kempner, Lucy Graham, and Frances Ratner.

Plus, each personal account is accompanied by a non-Autism Delaware slice of history that also happened in 1998. Look for the supplemental boxes entitled "Also in 1998"!

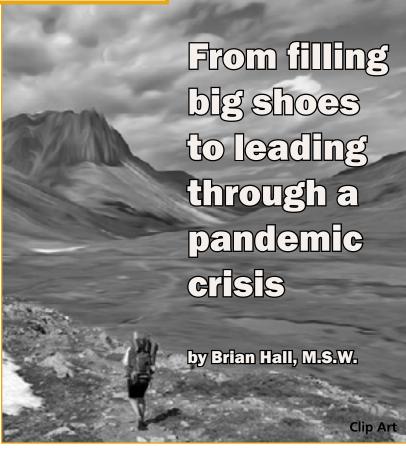


Our mission

To help people and families affected by autism







was hired in 2012 by Autism Delaware's executive director (ED), Teresa Avery, to be the agency's associate executive director. At the time, I had a background as a generalist in disability services: 19 years' experience directing residential and day treatment programs for children with moderate to severe behavioral problems and managing multiple home-visiting models of service delivery.

I learned quickly about the spectrum of services needed in the autism community. For the next couple years, I researched and strove to create more individualized residential services for people with autism while adjusting to the constant changes in the disability service environment.

I knew I had big shoes to fill when Teresa left in 2018. In addition to managing

Continued on p. 2







Autism Delaware

One statewide phone number (302) 224-6020

One statewide fax number (302) 224-6017

Email

delautism@autismdelaware.org

Website

AutismDelaware.org

Office locations

Newark 924 Old Harmony Rd. Suite 201, Newark DE 19713

Lewes

17517 Nassau Commons Blvd. Unit 1, Lewes DE 19958

Board officers

President: Rodger Pearce

rpearce@megee.co

Vice president: Michael J. Graci

mjgraci@me.com

Secretary: John Fisher Gray

John.F.Gray@dupont.com

Treasurer: Jeff Flanders

Jflanders3@comcast.net

The Sun

Managing editor: Dan Getman

Editor-desktop publisher:

Carla Koss

Contributors:

Cory Gilden Jen Nardo

Heidi Mizell Virginia Sticinski

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 <u>Carla.Koss@autismdelaware.org</u>.

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.

From filling big shoes Continued from p. 1

all direct service growth, I assumed oversight of all indirect programs and services during a critical period of much-needed expansion. The autism community was growing exponentially! As Autism Delaware's new ED, I promised not only that we would remain staunch advocates on behalf of individuals and families affected by autism, but also that I would direct the staff's energy and effort toward MORE—more family support services, more awareness, more community engagement, and more opportunities for community participation.

To do more, we had to balance service delivery with the infrastructure growth needed to build and maintain a growing community resource. Building on the mission initiated 25 years ago, we implemented new innovative and sustainable ways of improving services:

Within Autism Delaware's family support services, we

implemented a new parent-training series called Parent to ParentSM and a new one-on-one program for families called the Autism Care TeamSM (or ACTSM, for short). Autism Delaware trains both the Parent to Parent training facilitators and ACT's family support providers (FSPs) so they not only can help families navigate service systems and enhance their advocacy skills, but so they also know how and when to utilize their lived experience as caregivers of children with autism:

- As a participant in the ACT program, a family is assigned an FSP. Work is individualized, and each family prioritizes what it wants to learn, its goals, and the type of support it needs. Currently, Autism Delaware FSPs support 82 ACT clients.
- Parent to Parent is a five-week group training program for parents. The Parent to Parent training facilitators

coach the group in learning about autism, advocacy skills, and supports they may see in the autism community. The goal is to empower parents with a deeper understanding of autism and introduce them to information and supports they may encounter or ask their providers about.

In fiscal year 2022, Autism Delaware family support services reports 8,419 contacts our staff had with families.

Because adult vocational services focus on an individual's

needs, we added a personalized supportive-living model to Autism Delaware's complement of services. Originally called the community living assistance model, Autism Delaware's model today is authorized as a supportive-living model that comprises existing services with a funding structure that supports the training of personnel, ongoing management, and overhead costs. Services originate in the home but reflect the individual's person-centered plan. We address a variety of needs, such as assistance with adult daily living skills, strategies to support personal relationships, assistance with finances and bill paying, and when appropriate, clinical supports that address anxiety and obsessive-compulsive behaviors.

n addition to expanding family support and adult vocational services, I assumed my turn with the ED's newsletter column (which is usually printed on this page).

The Sun has become a leading resource for expertise, advocacy, and raising awareness in Delaware. Over the years, I'd read the topics that had been thoughtfully researched by the newsletter committee, so I could easily recommend the resources offered to enhance a family's journey.

Sometimes, the topic would expand

Continued on p. 3





From filling big shoes Continued from p. 2

my knowledge, too. For example, the autumn 2022 issue covered the changing language in the autism community. As a longtime proponent of people-first language, I learned that many autistics now prefer identity-first language. Acknowledging this preference allows for more inclusivity in the autism community—and further translated my generalist knowledge into autism-specifc outreach. I also remain sensitive to the part of the community that adheres to people-first language.

Leading through a pandemic

A year and a half into my tenure, COVID-19 hit. Suddenly, I had to figure out how to oversee the complicated, multilayered process of keeping staff members safe, employed, and paid while simultaneously addressing the loss of community partners and the subsequent loss of adult employment and community recreation opportunities.

Also, we had to cancel many in-person family support and community engagement programs to keep everyone safe. When possible, we offered virtual meetings, but many families continued to flounder and voiced their impatience with Autism Delaware's inability to meet their needs. Anyone who's read my column during this time is well aware of the difficulties faced by the staff as well.

Yet no one needed to tell the Autism Delaware staff that they are essential workers! As soon as Delaware Governor John Carney lifted the state of emergency, our staff immediately began expanding their workload to address the ill effects of COVID on our community. Thanks to these creative, optional resources—which did not exist prior to the pandemic—bright new opportunities began to fill the lives in our community. Slowly but surely, our families began to report positive outcomes. To share these highlights, Autism Delaware's family services staff created a social media campaign that provided a ray of hope to those who were struggling.

Meanwhile, the financial burden of running a nonprofit during a pandemic continued to fall not only on the shoulders of leadership but also on the entire Autism

Delaware community. Staff on our fund development and engagement team extended themselves beyond their usual outreach by creating online



Also in 1998

The National Association of Social Workers (NASW) celebrated "100 vears of social work accomplishment helping individuals, families and communities, and working for systemic changes to achieve social, political and eco-



nomic justice. The Centennial honored the social work profession's founders, champions and achievements in a yearlong celebration..... The NASW News featured profiles of the social work profession's most celebrated Pioneers" (https:// www.socialworkers.org/Events/Celebrations/Social-Work-Centennial#:~:text=In%201998%2C%20NASW%20led%20 a%20national%20celebration%20to,champions%20and%20 achievements%20in%20a%20yearlong%20celebration.%20

Among the celebrated Pioneers was social worker, suffragette, sociologist, philosopher, and Nobel Peace Prize winner Jane Addams (pictured above).

platforms that encompassed our first virtual Walk for Autism. In turn, many families were able to fundraise safely while enjoying themselves immensely.

And Autism Delaware's chief operations officer, Margie Rowles, and I worked tirelessly with our board of directors to keep our statewide offices open and our staff supported.

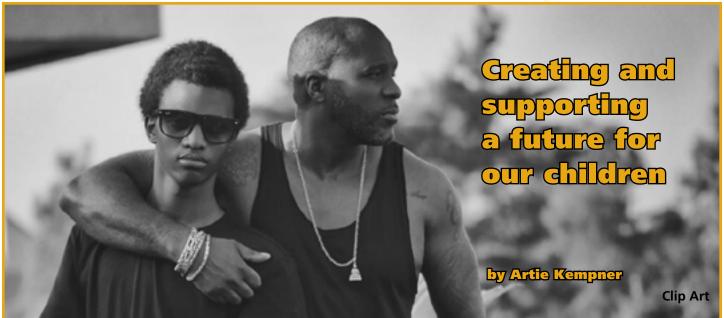
Today, I'm happy to report that our staff numbers are starting to bounce back, from 125 pre-COVID employees to 110. And thanks to an incredible effort by adult services staff, additional community partners have signed on, so we are now able to support 52 participants across the state.

With 2023 has come the opportunity to celebrate the hard Continued on p. 11

Brian Hall holds a master's degree in social work and is Autism Delaware's current executive director. He resides in Camden with his wife Shebra and their two children.







Our kids are going to be adults a lot longer than they are going to be children": This was the realization a group of parents had in 2003, led by Karen Bashkow and Marcy Kempner. At the time, Theda Ellis had been onboard as Autism Delaware's first executive director for about one year. Marcy's and my son, Ethan, was only eight, but Karen's son, Ben, was around 17 years old. So, Karen had a sense of urgency that the organization needed to get going on the road to adult services.

Ben was a big sweet kid with some challenging issues. Karen and Theda had started to talk to and educate our members about creating a future for our children when they became adults. We certainly had good resources for our school-aged children here in Delaware, but when they turned 21, most of those resources, including therapeutic programs and educational entitlements, would come to an end. Karen knew that we had to do something important to serve the needs of our most challenged individuals as they went into adulthood. With that mindset, Autism Delaware set a course to create and support a community-based adult services program, which became Productive Opportunities for Work and RecreationSM (or POW&RSM).

Creating financial support for POW&R

Since 1998, Autism Delaware had been fundraising through an annual gala and the Walk for Autism with pretty good success. Then in 2001, board member Pat Murphy suggested that we try to do a golf tournament. In 2002, we held our first Drive for Autism Celebrity-Am Golf Outing (The Drive). To support our effort, we had the good fortune of some close connections to sports stars across the Philadelphia area, Fox Sports broadcasters, NASCAR drivers, and the corporate racing community. We also were able to work with a volunteer team from MBNA Motorsports, led by then-senior executive vice president and director of MBNA Motorsports Dave Elgena, who helped us to secure more sponsors and celebrities—and the event raised \$175,000—a number that seemed incomprehensible when we had our first planning meeting in November of the previous year.

The next year, we hit \$250,000! With the help of the MBNA team, Fox Sports, N.K.S. Distributors, and an incredible group of volunteers led by past Autism Delaware staff member Cheryl Frampton, The Drive became something special. And it became a staple for NASCAR drivers, including series champions Jeff Gordon, Jimmy Johnson, Darrell Waltrip, Tony

Continued on p. 5



A 12-time Sports Emmy winner, most recently for directing Fox Sports coverage of NASCAR, Artie Kempner is also renowned for his work with NFL on Fox, including directing Super Bowls XLII and XXXIX. Also passionate about advocating for the autism community since his son, Ethan, was diagnosed in 1998, Artie helped found Autism Delaware plus the Fox Sports supports program and the AAA 400 Drive for **Autism at Dover International Speedway.**





Greating and supporting a future for our children

Continued from p. 4

Stewart, Rusty Wallace, Kevin Harvick, and Kurt Busch. In more recent years, we added to the list Joey Logano, Kyle Larson, Denny Hamlin, and so many others. The Drive became more than a charity event—It became a yearly meeting of friends!

From 2002 through 2007, we were able to raise close to \$2 million, which became the seed money to create the POW&RSM program. And we needed every penny of that seed money because we were building something from scratch.

Creating a nationally recognized program

Theda, Karen, and Marcy led a two-year research study to identify best practice and visited the best programs that could create and sustain a service delivery model that would truly help our adult

In 2008, a substantial grant to fund the startup was denied to us, but because of the money we had raised through The Drive, gala, and the Walk for Autism, we were able to take all the necessary steps to build something special. And we were able to hire Katina Demetriou as POW&R's director. An incredible

professional, Katina had the

magic touch in constructing a

nationally recognized program.

children as well as their families.

So many people helped us to raise the necessary funds to do what we do at Autism Delaware. and I'm thankful to all of them. Fifteen years later, those sponsors, donors, volunteers, and staffers are the reason the vision is a reality that continues to help so many POW&R participants to thrive.

Also in 1998

On the day before the 1998 Daytona 500. Dale Earnhardt who had never won the 500-milelong NAS-



CAR Cup Series motor race—met Wessa Miller as part of the Make-A-Wish program. She gave him a lucky penny that he placed on the dash before the race.

Right before meeting Wessa, Earnhardt had not been happy with his No. 3 Chevrolet in practice, yet he managed to stay out front for 107 of the 200 laps, including the last 61 circuits—and that day in 1998, Dale Earnhardt finally found Victory Lane in the Daytona 500 (https://www.nascar.com/ gallery/dale-earnhardts-1998-daytona-500-victory/).









From ineffective schooling to a happy and fulfilled adult life

by Lucy Graham, M.Ed.



he year was 1998. My husband and I had just moved our 16-year-old daughter and 11-year-old son halfway across the country to Delaware. By relocating from St. Louis, we were leaving behind the support of an extended family and many good friends. But our son Nick, who'd been diagnosed with autism in 1990, had been struggling with largely ineffective schooling. In those eight years, Nick had the benefit of an inclusive school experience from kindergarten through the third grade, but the special services needed to make the inclusion work were unacceptable: When I learned that my sweet, mild-mannered Nick had begun to spit at people in frustration, I visited the classroom—and found that they were covering his head with a paper bag to prevent his spitting rather than teaching him ways to appropriately communicate. That was the last straw for us.

When we found that Delaware was one of the few states in the country that had excellent public school services for students with autism, we said goodbye to our extended family and friends—and enrolled Nick in the Delaware Autism Program, which is known as DAP for short. Within weeks, he had learned to tie his shoes, he was using a fork and knife beautifully, and he was following routines and using pictures to state his preferences.

Important for me and my husband was meeting other parents who wanted more for their kids, too. They had joined forces to create the Autism Society of Delaware (ASD), which would eventually become Autism Delaware. As a natural outgrowth of ASD's advocacy efforts and DAP's excellent school program, a group of us parents began wondering how our children would be served throughout their lifespans. We realized that, once our children aged out of DAP's educational program, they had nowhere to go. How much would they lose without continuous training in adult life? Hard-won skills could be lost. Or worse, our children could be sitting home on the couch with nothing to do but watch TV.

Looking at what was available for adults with autism at the time, we decided we wanted something different for our kids. For example, our kids needed a community-based opportunity to work or volunteer in jobs that would suit their own individual interests and skill sets. Ideally, we wanted to partner with community businesses and organizations so that our kids could demonstrate their ability to be high-quality employees. To this end, we realized that participants in this new program would need to start gradually and transition from volunteer work to paid jobs. Yes, this opportunity was rare at the time, but it needed to be possible.

After much research and discussion, we parents constructed a program that, we believed, would adequately serve our adult children. I thought up a name that suggested strength while also covering our mission: Productive Opportunities for Work and RecreationSM, or POW&RSM, for short.

Continued on p. 7



Lucy Graham is a retired manuscript editor, kindergarten teacher, and librarian. She holds a master's degree in education and a bachelor's degree in journalism. Residing in Newark with her husband Dave and son Nick, Lucy is now working hard at building an independent living situation for Nick with all the supports he needs.





From ineffective schooling to a happy and fulfilled adult life Continued from p. 6

At the time, the recreation piece hadn't yet been realized—but how great it would be to round out my son's life with workouts, shopping, and other recreational pursuits! And the other parents agreed that this piece would benefit their adult children, too.

Today, POW&R is a nationally recognized program, and Nick is a POW&R participant with a volunteer position at a food pantry. My husband and I love the idea that Nick is productive while giving back to the community. Plus, the lifting and carrying he does at the pantry gives him the sensory input he needs, and the Autism Delaware and food pantry staffs work together to provide an inclusive setting. So, Nick comes home happy and fulfilled after a day of offloading trucks, stocking the pantry, and enjoying the camaraderie of fellow participants, POW&R staff, and the other pantry volunteers.

Also in 1998

I closely followed the news story of Andrew Wakefield's study and its conclusion that the MMR (measles/mumps/rubella) vaccine caused autism. Subsequent studies proved Wakefield had reported only the data that fit his thesis and had falsified his



data (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3136032/).

The moral of this story speaks to the importance of good scientific methodology and good data. I strongly believe in science-based research and intervention, which is the hallmark and measure for the Delaware Autism Program and also of the psychologists who have been involved as Autism Delaware staff.

As the parents of children on the spectrum, we weigh the health and medical needs of our children with good data possible only through adherence to the scientific method. When we have the facts, we can make good choices for our kids!

As I wrote about my family's journey to help Nick, I was aware that Autism Delaware's POW&RSM program could use some help in reaching its full potential. Thanks to COVID-19 and the Great Resignation, two factors have undermined the agency's effort to offer much-needed adult employment services:

- 1. hiring and retaining enough support staff plus
- 2. the loss of community partners offering jobs and volunteer opportunities

As a result, many new DAP graduates are waiting to transition into the program and many POW&R participants, such as my son Nick, have had their hours reduced.

My hope for Autism Delaware's 25th anniversary celebration? That POW&R's outreach efforts yield more good employees and community partners!

Thank you, Lucy Graham **To apply for a job** as an Autism Delaware direct support professional (DSP), click here.

To learn the benefits of becoming an Autism Delaware community partner, click here.





avbe when you go to college, and can reinvent yourself from, say, nerdy student to party animal. Maybe when you move to a new town, or change careers.

That's what I and the other founders of Autism (Society of) Delaware had in 1998—and we were able to build something from nothing. Personally speaking, I "gave birth" twice that year—first to Autism Delaware in May, and then to an actual baby in September.

Autism Delaware was younger, poorer, and dumber at the start. But, as the great Dr. Seuss would say, Oh, the Places We Went:



- How do we get more people involved—Let's have monthly meetings and form committees!
- We need to raise money—How about a silent auction!
- How do we better inform our community (the Internet was also in its infancy then)—We'll publish a newsletter, start an autism resource library, and invite experts in the field to our meetings!
- Families need autism-friendly social events—We'll have holiday parties (in our homes) and a picnic at Killens Pond!
- We want our legislators to increase autism research funding—We're lobbying in D.C.!

And that was just the beginning. In the subsequent early years, there were many more highlights, including additional social events (roller-skating, Blue Rocks, bowling), an all-day Autism Delaware conference, and Autism Delawarefunded research grants.

I am amazed at how far Autism Delaware has come in these 25 years. Sometimes I am wistful for those early days when the obstacles seemed large but the possibilities seemed larger. After I gave birth, I was fortunate to be able to take a long hiatus from paid work to devote myself to Autism Delaware. I particularly en-

joyed writing personal essays Continued on p. 9

Attorney Frances Ratner and her husband Steve Biener are the proud parents of three young women, one of whom is on the autism spectrum. As one of the founding members of Autism Delaware, Frances was very involved in the organization's early years. Currently, Frances sits again on the Autism Delaware Board of Directors and works as an assistant public defender in Wilmington.







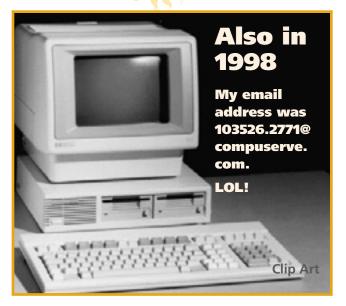
How often do you get a truly clean slate?

Continued from p. 8

for the newsletter, which I hope helped other parents and which definitely helped me work through my emotions at having a child with autism (my eldest). But organizations (and children) are only young once, and you just can't go back.

My child attended the Brennen School and is now an adult with a job and living in her own apartment. I still worry—but maybe not quite so much as before. As for me—I'm on the Autism Delaware board again, and I'm nearing the age when retirement from paid work looms on the horizon.

I guess that'll be my next chance at a clean slate.



Happy 25th Anniversary, The Sun!

n 1998, Frances Ratner created The Sun! As the first editor, not only did she write about her personal journey with a daughter on the spectrum, but Frances also assembled and published "All the Autism News that Fits." The four photocopied pages were hand-delivered to the parents of students enrolled in the Delaware Autism Program (or DAP, for short) at the Brennen School. The format may seem simple by today's standard, but the text covered the critical information that parents were

seeking at the time. Features included relevant news about autism, first-hand testimonials about treatments that families had tried, overviews of the parents' committee and advocacy work, and a list of upcoming events that the families could enjoy in the safety of each other's company.

In 2009, Cheryl Frampton helped direct *The Sun's* transition to a desktop-publishing format. Working in InDesign, Cher applied graphics and photos

Tell us!

Is The Sun changing your life for the better?

Or do you wish the newsletter had a different format or provided you with another type of information?

Please share your thoughts with us at delautism@

AutismDelaware.org.

to the text to create a more user-friendly publication. The newsletter was presented with its new look in the January–February issue.

In 2010, Carla Koss assumed responsibility for *The Sun* and was tasked with turning it into a leading resource for expertise, advocacy, and raising awareness of autism in Delaware. The quarterly newsletter added in-depth coverage of relevant research and best practice as well as singular topics important to the autism commmunity, such

as coping with grief and loss when the pandemic first hit and the current debate between identityfirst and person-first language. As a result, articles began coming in from autism communities around the country, and other voices were heard.

Today, an electronic version of *The Sun* is read by autistic individuals as well as their families, friends, the professionals who serve them, and their state legislators.







To every celebrity who ever enjoyed the Drive for Autism Celebrity-Am Golf Outing, thank you for fundraising and contributing your support to Autism Delaware's programs and services!

And to every volunteer who ever supported the Drive, thank you for making it possible for more fundraising dollars to be allocated to programs and services!

And to the many businesses, organizations, and individuals who ever sponsored the Drive, please know that your support has gone a long way toward helping people and families affected by autism. Our gratitude goes out also to the most recent sponsors of the Drive.



AAA Club Alliance

Aaron's Company

Adidas

AMG Sports

Austin Dillon Motorsports

Bill Harman

C-Ink

CMR Construction & Roofing

Crown Royal/Diageo

Currency Technics + Metrics

Denny Hamlin Foundation

eberl

FedEx

1st Down Sports

FOX Sports

Grotto Pizza

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Wade Siegel and Agron, Inc.







Meet Dan Getman

On February 1, Autism Delaware announced that Dan Getman joined the staff. The former senior manager of donor relations for a Philadelphia company that empowers people to improve their quality of life, Dan stepped into the position of Autism Delaware's fund development and engagement director. Responsible for meeting an annual revenue target, Dan is charged with achieving the agency's strategic vision and initiatives that translate into operational goals and priorities related to community engagement, philanthropy, stewardship, volunteerism, and communications. To this end, Dan will oversee all fund development initiatives while simultaneously

providing leadership to the fund development and engagement staff.

"I am incredibly excited and grateful for the opportunity to join Autism Delaware," says Dan. "As a fairly recent transplant to Delaware, I look forward to making an impact on the families in my adopted community."

"We are thrilled to get someone of Dan Getman's stature and abilities," says Brian Hall, Autism Delaware's executive director. "We intend to expand our services to meet the growing need in the community, and we expect to grow our financial support accordingly. So, we looked for the best in the development field and believe we've found it in Dan."



Dan Getman, CFRE (302) 224-6020, ext. 206

Dan.Getman@AutismDelaware.org

From filling big shoes Continued from p. 3

work and achievements gained by Autism Delaware over the past 25 years. As I drafted this article, we were revitalizing our family support and community engagement programs. (See page 12 for details.)



Plus, we were announcing our rebranding effort, which features a more inclusive logo (pictured here) and a redesigned website. And plans are underway for a vear-end celebration. As details are finalized, they will be posted on AutismDelaware.org

Looking to the future

I see several ways to improve Autism Delaware's viability. At the top of the list is remaining vigilant to the needs of the autism community. Two examples are increasing accessibility to applied behavior analysis (ABA) services and increasing opportunities to engage the community.

We also need to find ways to enlist input from our community and improve our communications, to be clear about what we do, and to learn how to be more consistent in acknowledging our successes as well as our challenges.

Please feel free to share your thoughts on how to improve Autism Delaware's viability going forward. As always, we welcome and appreciate feedback from you, our readers.

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INSIDE Autism Delaware

Revitalized programming

Family support services

April 26, May 24, June 28 Grandparent support group and coffee hour
Lewes office conference room. 9:00 A.M. Free. R.S.V.P.: Tomara Williams

April 26, May 24, June 28 Coffee hour for all primary caregivers

Virtual. 7:00 P.M. Free. R.S.V.P.: Heidi Mizell

April 27 Coffee hour: "Newly diagnosed? Start here!"

Virtual. 7:00 P.M. Free. R.S.V.P.: Heidi Mizell

June 22 Grandparent support group

Virtual. 7:00 P.M. Free. R.S.V.P.: Heidi Mizell

Community engagement

April 1 All About Inflatables (fundraiser to benefit Autism Delaware)
613 So. Main St., Bridgeville. \$7/person. Questions: Susan Campbell

April 22–23 DelAWAREness (dance showcase benefiting Autism Delaware)

Tatnall School, Wilmington.

For info, visit https://beataddikts.com/delawareness-charity-event

Autism Delaware continues to strive to revitalize our programming despite the ongoing COVID-19 pandemic and other emerging viruses. When you decide to take part in one of our programs, please gather safely.

Currently, we offer programs through both family support services and community engagement. Many are free, but others require an R.S.V.P. (reservation) or a ticket.

Noted here are the April–June programs that had been scheduled by *The Sun's* publication date. Check with the contact for more information.

For the up-to-date list, visit https://www.autismdelaware. org/events/.

