autismdelaware.org

The Sun

Newsletter

Winter 2020

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Our mission

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

Autism DELAWARE™

With the holidays over, this issue of* The Sun *focuses on well-being in the new year. The articles introduce nutrition as possible support for the management of autism symptoms, awareness of the effects of seasonal affective disorder (SAD) in someone with autism, and some ideas on what to do on a surprise snow day.

Can good nutrition help manage the symptoms of ASD?

by Virginia Sticinski, MEd

If you're like most families, the holidays are typically followed by a New Year's resolution focused on addressing the holiday weight gain. That's a noble goal, but for families with children on the spectrum, the effect of holiday overindulgence may be evident well beyond the waistline.

For example, some individuals with autism spectrum disorder (ASD) struggle with food-related issues that can affect their behavior. This leaves many parents searching for nutritional interventions. A diet that is gluten-free or casein-free (GF/CF) and the specific carbohydrate diet are among the most popular and are even lauded as potential "cures." But what does the evidence show?

The GF/CF diet is based on the premise that individuals with ASD lack enzymes to properly break down gluten (a wheat protein) and casein (a dairy protein). As a result, proponents believe these proteins can leak into the brain, causing behaviors typically associated with ASD.

Research to support this claim is limited though. For example, a recent study (Elder, JH, et al, 2015) reviewed over 27 publications evaluating the GF/CF diet, and determined there simply is not enough evidence to support the diet as an effective intervention. It is important to note, however, that parents who use this diet typically report improvements in their child's behavior (Piwowarcyk, A, et al, 2018). In other words, the evidence remains inconclusive.

The specific carbohydrate diet (SPC) is another popular choice among

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Autism Delaware™

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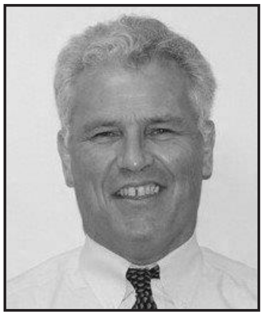
A lot more moving parts



Brendan O'Neill
President
Board of Directors

Since a small group of parents first met around a kitchen table more than 20 years ago, Autism Delaware has been attracting more and more families affected by autism spectrum disorder (ASD). For the fiscal year 2017–18, Autism Delaware fielded calls for help from 5,045 families—and is on schedule to surpass this number. And because Autism Delaware is a nonprofit whose only mission is to help people and families affected by ASD, the agency's fundraising dollars need to grow to support a staff capable of addressing the ever-growing need.

Currently working with an annual budget of about $4.5 million, Autism Delaware's executive director, Brian Hall, MSW, monitors and manages all these moving parts:

Autism Delaware operations director Margie Rowles handles the many issues faced on a daily basis by 119 dedicated and hardworking employees, including all human resources processes, electronic equipment maintenance, insurance coverage, federal and state taxes and regulations, and the processing of fundraising money.

The newly expanded family support program includes one-on-one family navigation and advocacy for both the English- and Spanish-speaking communities, parent education and support forums, partnering with the community on an array of activities, and individual and systems advocacy. Led by Autism Delaware family services director Annalisa Ekbladh, CPSP, the family support team now includes two family navigators (for English and Spanish speakers) and five family support providers as well as a resource coordinator for New Castle County and family services coordinator for Kent and Sussex Counties. Maintaining a care coordination approach for families, Autism Delaware's new intake coordinator manages the interview process when a call comes in and then schedules an appointment with the appropriate member of the family support staff.

Advocacy at the state and local levels is also run by Annalisa. As the autism agency's policy director, Annalisa is an effective advocate on the issues that are important to Delaware's families affected by

Continued in column 1 on p. 8

A service of Autism Delaware

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Clip Art

Is your child eating healthy?

To help answer this question, Swank Autism Center dietitian Natalie Moore, MA, RD, CSP, LDN, suggests a comprehensive nutritional evaluation that focuses on your child's typical intake.

Highlighting any nutritional adequacies and inadequacies, this look into your child's diet includes an evaluation of both macronutrients (such as carbohydrates, fats, and protein) and micronutrients. Also known as vitamins and minerals, micronutrients support growth, development, and overall health.

"If an inadequacy is identified, a target food can be added to help fill the gap," says Natalie. "For example, if a child is eating a variety of fruits, some dairy, protein, and grains, but no vegetables, the feeding therapy would focus on adding vegetables to the diet. This target food is introduced on a regular basis."

If it turns out that the child's diet lacks vitamins and minerals, a dietitian would have the resources for a more detailed nutrient analysis. The results not only pinpoint the needed vitamins and minerals but also list the best target foods for a balanced diet, adds Natalie.

Would my child benefit from a dietary supplement?

by Virginia Sticinski, MEd

Clip Art

The need for dietary supplements among individuals with autism spectrum disorder (ASD) is commonly debated and often questioned by their families. Some researchers suggest people with ASD are low in certain vitamins and minerals, and this deficiency may contribute to behaviors and symptoms associated with autism. Current research, however, is inconclusive—and leaves parents with more questions than answers.

Proponents of the biomedical model (which is used by physicians to diagnose disease) have generated interest in vitamin B-6, zinc, vitamin A, and fatty acids. Here's what is known about the theory behind each, and what the current research shows:

Vitamin B-6 is generally assumed to support speech, sleep, and attention span. Adding this supplement seems reasonable for individuals who experience problems in these areas; however, a comprehensive review cited in *What's the Scoop on Autism Disorders and Nutrition* (Wallace, 2009) found there was not enough evidence to support B supplementation for these symptoms. In addition, since high amounts of B vitamins can be toxic, supplementation without a doctor's consent can be dangerous.

Zinc and vitamin A are both associated with immune system function, and a deficiency is sometimes suspected among individuals who experience a weakened immune system. Recent studies (Sweetman, DU, et al, 2019) have looked at zinc and vitamin A levels among child participants on the spectrum and determined that their zinc and vitamin A levels were within normal range. This result suggests supplementation, at least for this population, is probably not necessary.

Fatty acids are commonly hailed as brain food, and a deficiency is thought to have a drastic effect on brain function. Some believe supplementation supports brain development and maintenance so, naturally, parents are curious. The results of a recent study (Mazahery, H, et al, 2019) are promising: Child participants on the spectrum showed improvement in some of their core symptoms. Follow-up studies are now needed to confirm these results.

Sources are listed at the bottom of p. 7

Feeding a difficult eater

by Allyson Davis, PhD

Pediatric psychologist at the Swank Autism Center at the Nemours/Alfred I. duPont Hospital for Children


Clip Art

"My child used to eat everything, but now we are down to the same handful of foods day after day": This is something that we hear consistently in our clinic because many parents of children with autism spectrum disorder (ASD) have concerns about the foods that their children are or are not eating. An almost universal experience among parents with children on the spectrum, chronic feeding difficulties are up to five times more likely than for parents with neurotypical children.

Children with ASD are often selective about their foods based on the type or category, color, brand, texture, or appearance. For example, children who are selective about the type of food they eat may refuse all vegetables, and those who prefer certain colors may end up eating only foods that are beige, brown, or orange—No Brussels sprouts!

Additionally, many parents are familiar with their child's rigorous inspection process that foods must pass before being considered edible. Given these food issues, parents often resort to providing the same meals each day, especially when the child has strong reactions or behaviors to new foods.

Not only do feeding difficulties frustrate parents, but they impact children in numerous ways. Nutritional deficiencies can lead to physical problems over time, even in children who appear to be growing and gaining weight as expected.

Also, many social events often involve food, and a family may avoid them to avoid the eating difficulty, but their child then misses out on a much-needed socialization opportunity.

If challenges during meals overwhelm you, one of the following strategies may help:

- Many children with eating difficulties show a preference for "grazing" (or snacking) throughout the day. They may appear to be eating more because they are eating more often, but snacking leads to lower food and beverage intake over the course of the day (when compared to scheduled meals and snacks). For this reason, keeping a set schedule for meals and snacks is important.

- While many of us may be motivated to try new foods, the new foods themselves do not motivate children with eating difficulties. Therefore, we may need to add external motivators in the form of reinforcements (such as a preferred activity, book, game, or toy). A reinforcement can be provided with a first-then contingency. For example: "First, eat one Brussels sprout; then, you can watch a video." Visual cues or schedules may also be helpful for showing your child what is expected first and what is coming after he or she follows your direction.

- For many children, "No" is the automatic response to "Do you want some Brussels sprouts?" To limit this power struggle, offer choices instead of asking a question. With a choice between a new or non-preferred food, a child can exert some control while still venturing outside of his or her comfort zone.

- Have a plan for managing the negative behavior that has contributed to the current limited diet. Negative behaviors often consist of refusal, avoidance, escape, or stalling. Because your child's goal is to get out of eating the Brussels sprouts, any way that accomplishes this goal solidifies the behavior. So your task is to prompt and reinforce positive mealtime behaviors while limiting the negative ones. And remind yourself: It really is possible for your child to eat new and healthy foods.

Have you experienced any of these with your child?

- **You have tried a variety of strategies without success.**
- **Your child has difficulty chewing or swallowing.**
- **Your child is eating only one food or less in one of the essential food groups.**
- **Your child has had changes in weight or growth.**
- **Your child gags or vomits during meals.**
- **Behavior concerns during meals have become overwhelming or too difficult to manage.**

If you answered "Yes" to any of these experiences, you may need professional help from a feeding specialist. For the name of a feeding specialist near you, contact Autism Delaware™ at (302) 224-6020, ext. 219.

SAD vs. ASD

by Liz Carlisle

Did you know: Shorter days and longer nights can bring on seasonal affective disorder (or SAD, for short). A mood disorder like depression and bipolarism, SAD appears more often in individuals with developmental disabilities than in the general population. Unfortunately, many of the symptoms—flat or depressed affect, reduced appetite, sleep disturbance, low energy, reduced motivation, and social withdrawal—can also be attributed to autism spectrum disorder (ASD). So, typical ASD behaviors make a SAD diagnosis difficult, especially if the individual can't communicate how he or she is feeling.

What should a parent look for?

Begin with your child's mood, appetite, and sleep patterns. You know how your child functions day in and day out. Are you noticing a change during the winter months? Does your child crave sweets or experience decreased energy and daytime fatigue, difficulty concentrating, increased agitation and anxiety, or a loss of interest in the things he or she typically enjoys?

How does SAD work?

According to the National Alliance on Mental Illness (NAMI), SAD is a major depressive disorder characterized by recurring episodes of depression in late fall and winter. These episodes alternate with periods of normal mood the rest of the year.

SAD is triggered by the brain's response to decreased exposure to daylight. While the reason for SAD hasn't yet been defined, current theories suggest that it has to do with the role of sunlight in the brain's production of the two hormones that regulate sleep, energy, and mood: melatonin and serotonin. When days are shorter, the brain produces more melatonin, which can cause drowsiness and lethargy. And serotonin production decreases with a decrease in sunlit hours.

How is SAD treated?

SAD may be treated with a light therapy box. As little as 30 minutes of exposure in the morning or afternoon can help alleviate the symptoms of SAD.

For children with sensory issues who may not be able to tolerate the brightness level, a good alternative is a dawn simulator, which gradually increases the amount of light being emitted.

If your child's symptoms worsen, a medical professional may help. Like depression, SAD can be treated with a combination of antidepressant medications, cognitive behavioral therapy, and exercise.

A light therapy box does not require a prescription and can be purchased through a variety of online outlets. Pictured above is one example, the Aurora LightPad Mini™ by Alaska North Lights.

A professional writer-editor with 30 years' experience in the healthcare, mental health, and behavioral health fields, Liz Carlisle has served on the Autism Delaware™ newsletter committee as a contributing writer-editor for the past five years and is the autism agency's current executive assistant and publicity coordinator.

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Yikes, it's a snow day!

by Carla Koss

What is the best way to handle an unexpected snow day? The short answer is "Make a plan." According to many experts—from the Australian government-supported website, Raising Children Network, to the Chicago-based Special Learning, Inc.—planning in advance is best for possible changes to a daily routine.

But if you need to go into action mode right now, below are a few tips from some of Delaware's blogging neighbors.

One strategy for making a plan includes creating a Social Story™. For more details, visit the Carol Gray Social Stories website at carolgraysocialstories.com.

Carol developed this well-respected evidence-based practice, which is used worldwide with people of all ages on the autism spectrum.

Create a schedule for the day


MORNING JOBS
BREAKFAST
QUIET PLAY
TV / QUIET PLAY
ACTIVE PLAY
LUNCH
REST TIME

SNACK
QUIET PLAY
ACTIVE PLAY
TV / QUIET PLAY
SUPPER
PLAY WITH DAD
NIGHT-TIME JOBS

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"Just keep the day simple!" notes Carolyn T. Bruey, PsyD, BCBA. "That way, you and your child can just relax and enjoy your day together (https://info.iu13.org/autism-solutions/5-rules-for-surviving-snow-days).

A board-certified behavior analyst in Lancaster, Penn., and coauthor of **The Autism Transition Guide: Planning the Journey from School to Adult Life,** Bruey posted *5 Rules for Surviving Snow Days for Families of Children with Autism Spectrum Disorder* on the Autism Solutions iu13 website. For the complete list, visit https://info.iu13.org/autism-solutions, and scroll down to the aforementioned post title.

Get out and play


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The snow can be your friend today, notes The Shafer Center website. Go out and make a snowman and snow angels, or go sledding. With other children out and about in the neighborhood, your child can practice his or her social skills—and maybe make a new friend.

Another possibility: "Get creative with some learning-based snow activities! Here are some of our favorites," notes the Owings Mill, Md., blog entitled *Oh, the Weather Outside Is Frightful...What To Do On Unexpected Snow Days!* "Use food coloring to draw shapes or letters in the snow. See what happens when bubbles are exposed to the cold. Fill up water balloons with colored water and let them freeze outside to make colored ice globes" (https://theshafercenter.com/2015/01/28/oh-weather-outside-frightfulwhat-unexpected-snow-days).

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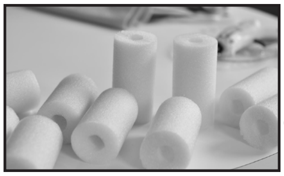
Indoor ideas

If your child prefers the indoors to the outdoors, some snow can be brought inside to paint. (Remember to buy some fake snow at a craft store before the next snow day.)

Or, as posted on AngelSense.com, do something totally un-wintery—like swimming in the Noodle Pool!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"Cut pool noodles down to six-inch lengths, and fill the tub (or a baby pool) with them. Softer than a ball pit, fun for 'swimming' or rolling around, but the benefits are still there. The brightly colored pieces offer sensory stimulation for children with special needs as well as strengthening motor skills" (https://www.angelsense.com/blog/5-winter-activities-for-kids-with-special-needs).

The complete blog can be found on the Pine Brook, N.J., website at https://www.angelsense.com/blog/5-winter-activities-for-kids-with-special-needs.

A two-time First State award winner for writing, Carla Koss has 25 years' experience as a writer-editor in the medical and disabilities fields, has served as managing editor for the Autism Delaware™ quarterly newsletter for the past nine years, and is the agency's current content strategist-writer.

Can good nutrition help manage the symptoms of ASD?

Continued from p. 1

parents. This diet requires the elimination of grains and sugars to help keep gut bacteria in balance. Though it was originally developed to treat celiac disease, many families with children on the spectrum have adopted this diet to help with both gastrointestinal (GI) disturbances and the ASD behaviors thought to be caused by a gut imbalance.

For more dietary resources or the name of the dietitian nearest you, call Autism Delaware™ intake coordinator Melanie Matusheski at (302) 224-6020, ext. 219.

Research supporting the effectiveness of the SPC diet in terms of treating GI disturbances is strong, but the jury is still out regarding its effectiveness in supporting ASD behaviors. Though research is limited, some case studies (Barnhill, K, et al, 2018; Gottschall, 2004) look promising.

Because each child is different, a diet that may work for one may not be effective for another. Moreover, any intervention must be nutritionally sound, so it's important to talk to your doctor before starting your child on any special diet. To help you determine if there is some basis for improvement, tests are available that identify gluten and casein sensitivities as well as GI disturbances, including bacteria imbalances.

Of course, don't underestimate the power of healthy eating. It stands to reason that—if a diet high in sugars and additives can have as negative an impact as on neurotypical individuals—a well-balanced diet can have as positive an impact.

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

Would my child benefit from a dietary supplement?

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A lot more moving parts

Continued from p. 2

ASD and their children. Her longtime connection to the autism community includes a stint with the University of Delaware's Center for Disabilities Studies; she's also the parent of a college-aged son on the autism spectrum.

Katina Demetriou runs the Autism Delaware™ adult services program, which is based on a unique adult service model that focuses on an individual's needs, interests, and outcomes through day-habilitation, social and wellness activities, and personalized supportive living services as well as the nationally known community-based vocational service known as Productive Opportunities for Work & Recreation™ (or POW&R™, for short).

As POW&R's longtime statewide director, Katina is supported in the southern part of the state by Autism Delaware assistant director Melissa Martin. Together, they coordinate an expansive team of direct support professionals (DSPs), their managers, and the community partners who support POW&R participants. Currently, POW&R supports 150 participants in paid employment.

Autism Delaware's awareness program—featuring the online resource guide, group email updates, website and social media, and this newsletter—has also experienced impressive growth.

The fund development and engagement team, led by David Woods, undertakes an ongoing effort to raise the funds that support the autism agency's current programs and services as well as to ensure sustainability going forward. To this end, David's team presents the statewide Walk for Autism and the ever-popular Blue Jean Ball. This team is also responsible for Autism Delaware's annual volunteer celebration plus support for third-party fundraisers across the state.

As you can see, Autism Delaware now has a lot more moving parts than it did when it began more than 20 years ago. With the addition of new staff comes the need for more volunteer support. So, please join our team of talented and celebrated volunteers who helps us meet our mission.

If none of the work I mention here is of interest to you, call for more ideas. Autism Delaware's community engagement specialist, Louise Doe, can be reached at (302) 224-6020, ext. 215.

Brendan O'Neill

Celebrating the season

Families affected by autism gathered across the state to celebrate the 2019 holiday season. More than 200 people participated at the Milford Elks Lodge and the Aetna Hose Hook & Ladder Banquet Hall in Newark.

Helping them to celebrate, Santa made an early appearance. He was supported by Holiday the Clown and Delaware juggler Cascading Carlos.

The party-goers also made ornaments and marshmallow snowmen to take home in addition to enjoying pizza from Grotto Pizza and Marino's Pizzeria.

The holiday raffle offered the winning ticket to Jolly Roger's® Splash Mountain in Ocean City, Md., in June.

Comcast community champion finalist honored with $30,000 donation for Autism Delaware

Left to right are Comcast 2019 community champion Mike Tatoian and award finalists Artie Kempner and David Ragan. The Comcast Community Champion of the Year Award was presented in November at the Hotel W South Beach in Miami in recognition of community service-focused effort made by individuals working in the NASCAR® industry.

Artie Kempner was honored at this year's South Beach, Fla., festivities celebrating Comcast's community champions. One of Autism Delaware's founders and a current board member, Artie is also an Emmy Award-winning coordinating director for NASCAR on Fox. The Comcast Community Champion of the Year Award recognizes individuals in the NASCAR® industry for their community service-focused efforts to make the world a better place.

As one of three finalists for the award, Artie was praised for his philanthropic work on behalf of Autism Delaware, alongside David Ragan, a Monster Energy NASCAR Cup Series driver and ambassador for Shriners Hospitals for Children®, and Dover International Speedway president and chief executive officer Mike Tatoian. Mike was given the 2019 Comcast Community Champion of the Year Award for his volunteer effort on behalf of the USO for the past 13 years as well as roles with the U.S. Air Force Civic Leader Program, the Military Bowl Foundation, and Dover Air Force Base.

“The three finalists all know each other through their connection to NASCAR and Dover events,” says Autism Delaware fund development and engagement director David Woods. “Because of his work with NASCAR on Fox, Artie has been able to create deep friendships and connections with NASCAR sponsors, teams, and drivers. These relationships have translated into a wildly successful golf tournament, the Drive for Autism Celebrity-Am Golf Outing, which is held each year on the Thursday before Dover's race weekend. Over the past 18 years, this event has raised more than $7,000,000 for Autism Delaware's programs and services.”

As a finalist, Artie was awarded a $30,000 donation for Autism Delaware.

Nominated by Autism Delaware fund development and engagement manager Deanna Principe, Artie has actively maintained his threefold connection to Autism Delaware as an autism advocate, a parent of a young adult with autism spectrum disorder, and as the Drive for Autism's chair. “We are grateful to Artie,” notes Deanna, “for his continuing effort on behalf of Autism Delaware's programs and services. None of them existed before Artie.”

“Many thanks to Comcast for its commitment to the nonprofit community and to Artie and NASCAR for this generous gift,” adds Autism Delaware executive director Brian Hall. “And of course, we are very pleased to congratulate Mike for his win and David Ragan and Artie for making this world a better place.”

Where does the money go?

While Autism Delaware spends five percent on management and general organization and seven percent is put back into fundraising efforts—88 percent goes into Autism Delaware's statewide array of programs and services, including the newly expanded family support program, advocacy, awareness, and the adult employment program known as Productive Opportunities for Work & Recreation (or POW&R, for short).

WALK FOR AUTISM

SATURDAY
APRIL 4, 2020

Cape Henlopen State Park
LEWES

SUNDAY
APRIL 5, 2020

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www.autismdelaware.org

DSP praised for "Doing Something Promising"

Autism Delaware direct support professional (DSP) Becky Anderson was honored by the Ability Network of Delaware (AND) in August at the 2019 DSP Day. AND's Community Excellence Award was given in recognition of Becky's outstanding service to people with disabilities and her role in building partnerships and supports that help individuals achieve success within the community.

Becky was praised specifically for her work with a 29-year-old individual who has challenging behaviors and requires significant support as a participant in Autism Delaware's adult employment program. Called Productive Opportunities for Work & Recreation™ (or POW&R™, for short), this program is Autism Delaware's unique adult service model that focuses on individual needs, interests, and outcomes through day-habilitation, social and wellness activities, and personalized supportive living services as well as community-based vocational services.

In addition to transitioning the POW&R participant into both a new work site and a group home, Becky helped the young adult—who has been nonverbal most of his life—to learn to communicate through sign language. Becky also supports this individual as he volunteers at the Milford Library and Sussex Academy Aquatics Center and does light housecleaning for a fellow POW&R participant.

The most meaningful piece of her work is developing a relationship with her POW&R participants, notes Becky, "and seeing them move to the next independent level. There are so many opportunities to shape the neurotypical community's behaviors around autism and to help adults on the spectrum become active participants in that community." To this end, the award-winner has redefined the abbreviation DSP to "Doing Something Promising, that is, putting your feet into action and coming up with a plan for success."

Becky Anderson, DSP in Autism Delaware's Sussex County office, won AND's Community Excellence Award

An underfunded work force

In honoring the outstanding effort of direct support professionals (DSPs), organizations like the Ability Network of Delaware (AND) hope to call attention to the underfunding of the state's valuable and dedicated work force.

"The average DSP makes just $11.50 per hour," says Autism Delaware executive director Brian Hall. "This is not a living wage and can lead to employee turnover and diminished quality of care. This inadequate funding stresses the entire system and puts adults receiving services in danger.

"Better-trained staff members who stay on the job longer will result in better care and a safer environment for adults with intellectual and developmental disabilities," adds Hall, "and help prevent costly hospitalizations and institutionalizations."

Addressing this long-debated issue, the Delaware General Assembly passed the Michael McNesby Act in 2018. This mandate increased the rate paid to providers (such as Autism Delaware and AND) so they can raise the DSPs' pay; however, the increase lags behind the benchmarked rate. As a result, Autism Delaware, AND, and other social services agencies must continue to advocate for the annual increases needed to bring the funding up to the recommended market rate.

A living wage for direct support professionals (DSPs) is just one of the issues that Autism Delaware advocates for on Smart Cookie Day in April. To learn more, contact Autism Delaware policy and family services director Annalisa Ekbladh at (302) 224-6020, ext. 218. Or send an email of interest to Annalisa.Ekbladh@delautism.org.

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Helping People and Families Affected by Autism

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Autism Delaware has been helping people and families affected by autism for more than 20 years.

With today's national prevalence rate of one in 59, many more families are beginning the autism journey—and they face a lot of fear and a lack of resources.

With your donation, Autism Delaware can continue to support more families.

Yes, I want to help a family today!

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