



THE SUN

WINTER 2025

The quarterly newsletter for people on the spectrum, their families, and the professionals who support them:

We at *The Sun* strive to be the leading resource for expertise, advocacy, and raising awareness as well as for supporting acceptance and inclusion in Delaware.

Autism Delaware's family support team has recorded an unprecedented number of calls about the state's new process for granting respite services to children on the spectrum. Many newcomers to the state are asking questions about respite services as well.

To answer their questions, *The Sun* reached out to Delaware's Department of Health and Social Services' Division of Medicaid and Medical Assistance (DHSS DMMA) and the Division of Developmental Disabilities Services (DHSS DDDS).

Many grateful thanks to

- Andrew Wilson, DHSS DMMA director;
- Colleen Yezek, chief of managed care operations;
- Donna O'Hanlon, senior social service administrator; and
- Stacy Watkins, DHSS DDDS deputy director.

Their knowledge and resources provided the information for this cover story.

The new path toward respite services

by Carla Koss



In Delaware on January 1, 2023, the Department of Education (DOE) Office of Statewide Autism Programs (or DOSAP, for short) handed over responsibility for respite services to the Department of Health and Social Services' Division of Medicaid and Medical Assistance (DHSS DMMA). Where DOE services had been assessed for an educational classification of autism, DMMA's assessment focuses on medical necessity.

A letter notified the families of children on the spectrum who had been receiving DOSAP respite services. In this correspondence, the DHSS Division of Developmental Disabilities Services (DDDS) assured families that their children would continue to qualify for respite services: "We have continued to inquire about enrollment status as respite requests are received," wrote DDDS deputy director Stacy Watkins, "and, once verified that a family has not yet

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AutismDelaware.org

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Blessings and life lessons

Running here and there... Go! Go! Go! Life can get crazy—and so much noise is swirling around our lives! Before I know it, I'm exhausted. I have to force myself to take a breath. When I can finally chill, the noise clears. I can hear myself think—and I can count my blessings.

My daughter Hope is my great blessing. She has a natural knack for seeing blessings all around her all the time—whereas I, a neurotypical man, have to stop and focus on that specific purpose. In some ways, Hope and I are like Lucy and Charlie Brown: In one of our favorite movies, *It's the Great Pumpkin, Charlie Brown*, Lucy gets the lollipop while poor Charlie gloomily admits—Let's all say it together—"I got a rock."

At this point in the movie, Hope pipes up: "Hey, rocks are good. You can draw on them. You can glue jewels on them. You can make a rock garden. You can throw them in a pond..."

Geez, how many life lessons have I learned from Hope!

If you're anything like me, I'm sure you, too, have gloomily admitted at one time or another that all you had been given was rocks. So, let's stop for a moment and practice one of Hope's life

lessons: See the many blessings all around us.

Autism Delaware is a tremendous blessing because of the agency's many programs and services: Some for families with newly diagnosed loved ones. Some for the grandparents of loved ones on the spectrum. Some that offer supported employment. Some to help our adult program participants in the community.

Plus, if you have a problem, the staff at Autism Delaware will help you solve it. For example, if you're struggling with a child's behavior issues, staff members will come alongside to assist you in making a plan. Or if you have moved recently to Delaware and are looking for resources, the staff can help with this also.

Furthermore, if you have a specific question, staff can help you get the answer. From struggling with behavioral strategies to figuring out the state's educational and Medicaid systems, Autism Delaware's staff can help.

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Rodger Pearce
President
Board of Directors

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The new path toward respite services *Continued from p. 1*

Any service, such as respite, must be authorized through a person-centered plan. DDS's authorized provider is The Columbus Organization (TCO). For an explanation of TCO's services and how to apply for them, see the article on page 4.

Newcomers to Delaware

You must first establish residency before applying for Medicaid. This requirement includes maintaining a home in the state and residing in it for more than 183 days. More information for newcomers can be found on page 6 in this newsletter. For an online guide to becoming a Delaware resident, [click here](#).

been able to enroll, we are approving the requests to ensure no one is left without access to this valuable benefit.”

Watkins's letter also announced a new name for the DMMA respite services: the Pediatric Medicaid Respite Benefit, which is available up to age 21.

Anyone applying for the Pediatric Medicaid Respite Benefit for the first time needs to take the following three steps.

Step 1: Apply for Medicaid: Apply through the state's [DMMA ASSIST Portal](#).

Children determined eligible for Medicaid are enrolled in the Diamond State Health Plan (DSHP), a mandatory Medicaid program that operates under an 1115 waiver with approval from the federal Centers for Medicare & Medicaid Services

(CMS). With DSHP enrollment, eligible children are issued Medicaid insurance cards.

Step 2: Enroll in a managed care organization.

Called an MCO for short, a managed care organization delivers the child's comprehensive health coverage. In Delaware, there are three MCOs, which are listed in the yellow box with their phone numbers.

All three MCOs offer the same respite benefit for children up to age 21. New Medicaid members are encouraged to call the health benefits manager (or HBM) to select their MCO.

Once an MCO is selected, continue the path toward respite services by calling that MCO and asking for a care coordinator. The child will receive an MCO card as well as the previously mentioned Medicaid insurance card.

How to switch MCO plans—

New Medicaid members have 90 days to switch assigned plans. Established Medicaid recipients may switch plans during the annual open enrollment period every October.

Step 3: Hire a respite provider.

Families have two options for hiring a respite provider:

1. Ask the MCO care coordinator for help finding a respite service provider. The family will be able to

Delaware's Medicaid MCOs and their phone numbers

- > **AmeriHealth Caritas DE**
1-844-211-0966
- > **Highmark Health Options**
1-844-325-6251
- > **Delaware First Health**
1-877-236-1341

For questions about selecting or switching an MCO plan, call the HBM at 1-800-996-9969.

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Autism Delaware content strategist-writer Carla Koss has 30 years' experience researching, writing, and editing articles relevant to the disabilities community in Delaware. She is also a two-time recipient of the First State Award for Writing for her work with the National Multiple Sclerosis Society and the University of Delaware's Center for Disabilities Studies.



About The Columbus Organization

by Jennifer Tozer

The Division of Developmental Disabilities Services (DDDS) partners with organizations to provide targeted case management for individuals and families who meet the eligibility requirements for DDDS services. Currently, [The Columbus Organization](#) serves as DDDS's authorized provider for targeted case management, supporting individuals who live with their families or independently.

Community navigators employed by The Columbus Organization play a crucial role in helping individuals and families connect to resources, access services, and develop a person-centered plan. This plan is essential for obtaining adult services through Delaware's §1915(c) Home and Community Based Services Waiver, the [Lifespan Waiver](#). The Centers for Medicare & Medicaid Services (CMS) requires all states to demonstrate person-centered planning and service delivery for participants, ensuring that services meet the unique needs of each individual.

In 2017, DDDS expanded the Lifespan Waiver to include services for individuals living at home and adopted the [Charting the LifeCourse](#) (CtLC) framework for person-centered planning. This framework provides guiding principles and tools to help all individuals and families plan for the future and navigate life's transitions.

Getting started

Applying for DDDS services can happen at any stage of life, starting as early as age 3. There are two options for applying. Individuals or their parent/guardians can apply either online through the [DDDS website](#) or submit a paper application to the DDDS Office of Applicant Services.

Until an individual reaches the age of 22, DDDS reserves the right to review updated assessments and redetermine eligibility at any time, including requiring additional testing that must be completed prior to the age of 22. In most cases, eligible applicants

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are enrolled in DDDS’s system and referred to The Columbus Organization for targeted case management services.

Adult applicants (18 or older) enrolled in Delaware’s Diamond State Health Plan Plus Program receive case management services through their managed care organization (MCO). These individuals are not referred to The Columbus Organization for community navigation. (For more about MCOs, see the article in this newsletter starting on page 1.)

For those eligible, a representative from The Columbus Organization will reach out within 30 days to gather information and assess any immediate needs, such as emergency assistance or respite.

Once assigned, individuals and families can expect routine contact with their community navigator. This support ensures that the planning process is consistent and that families have ongoing access to resources and information.

Planning across life stages

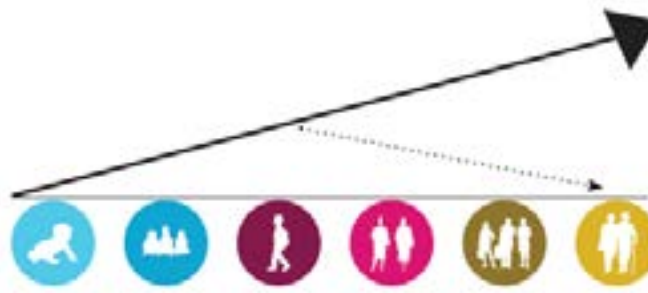
Person-centered planning recognizes that people are part of a family unit and that their life experiences are shaped by their relationships within the family and community. DDDS is committed to becoming a more person-centered organization, using tools that help individuals and families explore their goals and vision for a good life.

A person-centered plan outlines the supports and services individuals need to live meaningful experiences across their lifespans. The role of the community navigator is to guide this process, providing consistent access to resources and helping support smooth transitions between life stages and service

systems. This plan should complement other plans, such as an individualized education program (IEP), and address caregiver respite needs, too.

Monitoring and updating

When a recipient receives services through the expanded Lifespan Waiver, community navigators monitor the person-centered plan, including any services provided, to ensure the services meet the individual’s needs and goals and are delivered as described in the plan. Planning in early life stages can help support the individual and family as they consider and prepare for anticipatory needs. Plans are updated at least once a year, but they can be revised whenever circumstances change.



Graphic courtesy of Delaware DHSS DDDS

Preparing for person-centered planning

While the community navigator facilitates the process, the individual’s goals and needs drive the plan’s development. It’s normal for people, especially young adults, to be uncertain about their future goals, but they often know what they want to avoid. Planning may begin by identifying these preferences.

DDDS encourages all individuals, regardless of age or ability, to actively participate in their planning to the fullest extent possible. The person-centered planning process includes the individual’s circle of support and any service providers. Also, a parent who is the legal guardian is automatically included in the planning process. This collaborative approach ensures that everyone involved understands their roles and responsibilities in creating a plan that truly reflects the individual’s aspirations.

To connect with Jennifer, you can call 302-836-2100 or email her at Jennifer.Tozer@delaware.gov.



Jennifer Tozer began her career in human services in 2004 and joined the Division of Developmental Disabilities Services (DDDS) in 2015. Currently, she serves as the manager of family engagement and is a division facilitator in the community of practice. Jennifer’s passion for working with the disabilities community began as a teenaged volunteer at Special Olympics. This experience sparked a belief that every person has the right to live life authentically. Outside of work, Jennifer is a musician, artist, avid disc golfer, and the mother of two very kind humans, two dogs, and two ornery kittens.

The newcomer's guide

Meeting a child's needs in your new home state

by Tomara Williams and Carla Koss; Dafne Carnright, LPCMH, BCBA (Ed.)

**Autism Delaware
admissions department**

302-224-6020, ext. 219

Meeting the needs of an autistic child may loom large and scary on the horizon, especially for a family who has recently moved from out of state. But in Delaware, it boils down to four simple steps on the parent or caregiver's part—and Autism Delaware's family support team can help with assistance that addresses your specific needs.

Step 1: Consider applying for Medicaid.

Medicaid is a federal entitlement under Title XIX of the Social Security Act of 1965. It is not a charity or philanthropic organization, but a medical assistance insurance program. Eligibility is determined by the family's income and resource level.

Delaware has a special Medicaid program for children with disabilities who are under the age of 18. Called the Children's Community Alternative Disability Program (or [CCADP](#), for short), this Medicaid program does not depend on the parent's income or assets; instead, it's based on the child's assets and income. To talk to an Autism Delaware family support team member about CCADP, call Autism Delaware's admissions department and ask for an appointment.

Did you establish residency?

You must first establish residency before you can address the four steps for meeting your child's needs. For help establishing your residency in Delaware as well as resources for in-state driving, voting, working, housing, and schooling, [click here](#).

Step 2: Enroll your child in school—if he or she is under the age of 22. Contact your home school district to begin the registration and enrollment process. But if this step feels like too much to manage, call Autism Delaware's admissions department and ask for an appointment with a family navigator.

If your child is 22 or older, click [here](#) for information about Autism Delaware's adult services program. Or call Autism Delaware for assistance in find-

ing an adult program that fits your child's specific needs.

Step 3: Learn the state's special-education process and programs.

Autism Delaware's family support team not only can help you understand the state's systems, but the team can also help with your child's individualized education program (IEP).

Step 4: Bridge any gap in your child's services by connecting with collaborating agencies, such as Delaware's Division of Developmental Disabilities Services, Division of Vocational Rehabilitation, and Pathways to Employment, to name only a few. Autism Delaware can also provide helpful information to assist with navigating these resources.

Blessings and life lessons *Continued from p. 2*

Look closely at all these programs and services, and you'll happily admit that they have one common theme: They all involve rock solid people helping the people we love on the spectrum. And this is a major blessing.

As the agency's board president, I see all the behind-the-scenes workings, and I know that the staff and the board of directors pinpoint their focus on one person: the wonderfully awesome individual who you love and who also teaches you incredibly awesome life lessons.



Meet our new bilingual admissions specialist

Elizabeth “Liz” Lichtenstein joined Autism Delaware in September as the newest bilingual member of the admissions team. Her responsibilities include responding to new requests for family support services, explaining the various available services, collecting demographic information from callers, and setting up the family’s first appointment either

with a family navigator or by enrolling the family in the ACTSM (Autism Care TeamSM) program.

An émigré from Puerto Rico, Lichtenstein began establishing roots in Delaware in 1999. She has worked a range of jobs, including as an ESL (English as a second language) tutor at Claymont Elementary School and on the front desk at the Elsmere Library. She also writes short stories, novels, and children’s books. Accolades for her work include the 2023 Delaware Individual Artist Fellowship and first place in the 2023 Delaware Press Association Communications Contest plus the 2023 NFPW Professional Communications Contest. Most recently, Lichtenstein was awarded the 2024 Artist Opportunity Grant from the Delaware Division of the Arts.

To support Delaware’s literary and arts community in turn, Lichtenstein co-founded The Hockessin Art & Book Fair’s Anime Day at the Art Studio and founded a small comic book convention. Called Bento Con, the effort resulted in a tribute from Delaware’s House of Representatives.

Also the mother of two sons on the spectrum, Lichtenstein points to her empathy and passion for helping others as the reasons for now working in the autism community: “I wanted to be able to help parents and caregivers who struggle like I did when I was taking care of my kids and trying to find resources to help them in their journey. I was constantly searching for answers and ways to help my kids. And most of the time, it feels very lonely, like it’s just you and your instincts keeping things going.

“I’m beyond happy and proud to be here at Autism Delaware, working with this incredible team of people. I’m inspired every time I come to work, knowing that even if it’s something small, I’m helping someone and making their life a little better.”

Reach Liz Lichtenstein in the admissions department by calling 302-224-6020, ext. 219, or by emailing her at referrals@autismdelaware.org.

Programs and events

Autism Delaware strives to offer a range of educational and fun programs and events in safe and inclusive settings.

Everyone in the family can find an activity to enjoy: from weekly bowling nights and sensory friendly roller skating to parent-to-parent workshops and coffee hours.



For the most up-to-date listing, [click here](#).

New DHSS support network

The Delaware Department of Health and Social Services introduced the Delaware Caregiver Action Network in October. Called DCAN for short, this program has been formed to empower caregivers, connect them to information and resources, and amplify their voices at the state level.

Are you interested? Send an email to DHSS_DCAN@delaware.gov.

One Walk—One state—One day—One mile

Help us create the largest celebration of inclusion in Delaware!

This year, Autism Delaware is bringing all three counties together for one big celebration during Autism Acceptance and Inclusion Month.

With three starting times to choose from, you and your family and friends will have plenty of opportunity to enjoy the day's festivities.

2025 Walk for Autism

presented by Delmarva Corrugated Packaging

Where?

Dover Motor Speedway

When? Saturday, April 12

What's your start time?

- > quiet walk at 9:00 AM
- > 12:00 PM
- > 3:00 PM

How do you register?

Click here!



Need help forming and supporting a team?

Ask Kris Grant

- > 302-224-6020, ext. 217
- > Kris.Grant@autismdelaware.org



What's the POINT in volunteering?

It's a new, easy-to-use app that makes volunteering a snap!

Plus, it's an easy step toward joining Autism Delaware's much-appreciated family of volunteers while supporting the autism community.

Why are Autism Delaware volunteers appreciated so much?

Because they lend a helping hand when needed at programs and events, which in turn helps us save more of our fundraising dollars and cents for much-needed programs and services.

Want to give it a try? [Click here!](#)

Got questions?

Ask Susan Campbell:

> 302-983-4338

> Susan.Campbell@autismdelaware.org



Join the Walk for Autism Grand Marshal Kevin Williams, Jr., and his family for this year's one-day event. Left to right are his mom Tomara; Kevin, Jr.; his dad Kevin, Sr.; and sister Charity.

The new path toward respite services Continued from p. 3

choose the respite provider that best suits their child's needs.

2. Hire a family member or friend to provide respite care. Called self-directed attendant care (or SDAC, for short), this respite benefit is supported by one of three financial management services (or FMSs) in Delaware: Easterseals, JEVS Human Services, and GT Independence.

Each FMS defines the family member or friend as a "self-directed employee" who assumes respite care duties. In turn, the child's parent or legal guardian is defined as the FMS's "employer representative." In this role, the parent or guard-

Each MCO sets its own plan rate for SDAC, and each FMS has its own pay scale. Anyone interested in learning this information should speak to their MCO care coordinator. The care coordinator can also provide contact information for the FMS.

ian doesn't provide the respite care but directs it with support from the FMS.

Examples of FMS support range from help with hiring, supervising, evaluating, and discharging self-directed employees to receiving, processing, and approving time sheets and processing payroll.

Help establishing the SDAC process as well as help coordinating it with the child's physician is available from the MCO's care coordinator. The MCO care coordinator can also help determine a child's eligibility for services, track hours of care, and change the hours of care when it's medically necessary.

Sources

Division of Medicaid and Medical Assistance: Self Directed Attendant Care for Children. Standalone worksheet. (Delaware Department of Health and Social Services' Division of Medicaid and Medical Assistance, 2023.)

O'Hanlon, Donna. Autism Delaware respite article. Email, 2024.

O'Hanlon, Donna. Cover story for Autism Delaware newsletter. Email, 2025.

Steps to Access Home Health Aide Services (agency based or self-directed attendant care). Standalone worksheet. (Delaware Department of Health and Social Services' Division of Medicaid and Medical Assistance, 2023.)

Respite Options, New Medicaid Pediatric Respite Services, Family Session. PowerPoint presen-

tation. (Delaware Department of Health and Social Services' Division of Medicaid and Medical Assistance, May 2023.)

What is Respite? Handout. (Delaware Department of Health and Social Services' Division of Developmental Disabilities Services, August 2024.)

Watkins, Stacy L. Letter to service recipients and families. Dover, Del. Delaware Department of Health and Social Services' Division of Developmental Disabilities Services. January 30, 2023. URL: <https://dhss.delaware.gov/dhss/ddds/files/RespiteBenefitLetter013023.pdf>.

Watkins, Stacy L. Info about respite care services. Email, 2024–2025.

Yezek, Colleen. Autism Delaware respite article. Email, 2024.

