

The Sun

Newsletter

October–December 2016

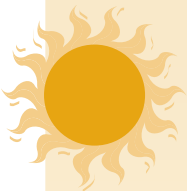
Inside this issue

Inside Autism Delaware 4–6

Parent2Parent 7

A look at SSI benefits 8–10

Q&A with a Social Security disability attorney 11



Our mission

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



What I wish every parent knew about Medicaid

As both the parent of a young man with special health-care needs and the executive director of Delaware Family Voices®, I speak to many parents and try to help them navigate the many health-care systems—including Medicaid.

It is not uncommon, I've found, for parents of children with special health-care needs—such as autism spectrum disorder—to feel like they are at least two steps behind in what they need to know to get beneficial services and resources for their children.

One of the first things we need to have in place is the insurance that will, hopefully, cover most if not all of the costs of our children's medical needs. Without proper coverage, medical costs can quickly add up to an insurmountable debt. Also, many parents go from a two- to one-income family because one parent must devote more time to coordinating the child's care, navigating the systems, and doing anything else that needs doing.

Though many different types of Medicaid programs exist, I am going to cover those most commonly needed by children on the spectrum. Below is some condensed information as well as contact information and other resources that may help you.

For children under 18, there is a Medicaid program based on the income of the parents. Children do not have to have a special health-care need to qualify. To apply for this program, call Medicaid customer relations at (302) 571-4900. Or apply online at <https://assist.dhss.delaware.gov>.

Another Medicaid program is based on the special health-care needs of the child. Called Children's Community Alternative Disability Program (CCADP), this program considers what's typical for your child's age. For criteria, visit the Medicaid website at <http://dhss.delaware.gov/dhss/dmma/disabledchildren.html>. For assistance, call the Delaware Helpline at (800) 464-4357. And for CCADP and adult long-term-care services, call your county's state service center's long-term-care unit. Or call the central intake unit at (866) 940-8963.

Be certain to specify which program you are applying for.

Medicaid for children ends at age 19, but you can apply until age 18. For many of Delaware's Department of Health and Social Services (DHSS) programs, you may apply online at <https://assist.dhss.delaware.gov>.

About Medicaid and MCOs

Medicaid is a state agency. Once you or your family member qualifies for Medicaid, you will be asked to select a managed-care organization (MCO). Currently in our state, we have two MCOs to choose from: United Healthcare Community Plan and Highmark Health Options. These are the insurance companies that Medicaid contracts with to provide insurance and services under Medicaid.

Once you choose an MCO, you will receive a Medicaid card from the state and another card from the MCO. These are *not* two separate insurance programs; you actually

Sun contributor Ann Phillips is executive director of Delaware Family Voices. The parent-run nonprofit's mission is to better serve Delaware families and their children with special health-care needs.

Autism Delaware™

Newark

924 Old Harmony Rd.
Suite 201, Newark DE 19713
Phone: 302.224.6020

Dover

c/o Dover Downs
1131 North Dupont Hwy., Dover DE 19901
Call for on-site appointment:
302.224.6020 or 302.644.3410

Lewes

17517 Nassau Commons Blvd.
Unit 1, Lewes DE 19958
Phone: 302.644.3410

Email

delautism@delautism.org

Website

autismdelaware.org

Family support

Kent and Sussex Counties

Dafne Carnright
Family service coordinator
dafne.carnright@delautism.org

New Castle County

Heidi Mizell
Resource coordinator
heidi.mizell@delautism.org

Officers

President

Pete Bradley
pbradley@doverdownsslots.com

Vice president

Marie-Anne Aghazadian
elisa945@gmail.com

Secretary

John Fisher Gray
john.f.gray@dupont.com

Treasurer

Jeff Flanders
jflanders@midcoastbankonline.com

The Sun

A publication of Autism Delaware

Editorial committee

Carla Koss
Ann Athas Cory Gildea Heidi Mizell
Liz Carlisle Gail Hecky Jen Nardo
Dafne Carnright

Autism Delaware™, POW&R™, Productive Opportunities for Work & Recreation™, and the Autism Delaware puzzle-piece logo are trademarks of Autism Delaware Inc.

Navigating unfamiliar waters

If you or your loved one have a disability, you may sometimes feel like you're paddling across an unknown sea without a compass—or even a paddle! Connecting to needed services—as well as payment for these services—means navigating the intricacies of state- and federal-level systems that are far from easy to master.

During your journey through the world of disabilities services, you most likely learned a new vocabulary that you never expected to learn. I know, the first time I heard the word “waiver” used in the disability community, I was entirely confused: “‘Waiver’? What are we waiving? Is there some sort of fee that people don't have to pay?” Even when the fuller descriptor was used—“Medicaid waiver”—I was none the wiser.

On top of this new vocabulary is the alphabet soup of abbreviations and acronyms: DDDS, DVR, DOE, ICAP, IEP, CDW, DAP, and on and on. You may find yourself in need of a little help navigating unfamiliar waters as you work with your child's school on your first IEP, get ready to apply for SSI, or research the SSDI options for adults with autism.

How can Autism Delaware help?

Information—This issue of *The Sun* is an example of the type of information we provide to individuals and families as we work to make life a little easier for you. The cover story, Parent2Parent segment, and articles on page 8 and 11 feature information parents should know when applying for Supplemental Security Income (SSI) for their children.

Additionally, the Autism Delaware website has more information on many topics, our Facebook page provides daily updates on activities, and our Google group email list is a smorgasbord of information.

You can decide if one or all of these options work well for you.

Parent mentors—If you're only beginning or have come to a difficult spot in your journey, our parent mentors are here to help. They can answer your questions, connect you to the resources you need, and share their own experiences and what they've learned over years of working with families affected by autism. For help in northern Delaware, contact Heidi at heidi.mizell@delautism.org. In southern Delaware, email Dafne at dafne.carnright@delautism.org.

Advocacy—Not all the resources needed by families are available in the way they are needed—either here in Delaware or around the country. In these cases, it's time to advocate for a change. Autism Delaware supports families who want to help make these changes. So, if you have an issue you want to see advocated—or if you want to learn more about what's going on at the state and federal level—contact Alex at alex.eldreth@delautism.org.

We're here for you! Call us when you need us.



Teresa Avery
Executive Director

A service of Autism Delaware



Katina Demetriou, director
katina.demetriou@delautism.org
Bus: 302.224.6020 Ext. 202 **Cell:** 302.824.2252

Melissa Martin, assistant director
melissa.martin@delautism.org
Bus: 302.644.3410 **Cell:** 302.824.9710

Kim Rosebaum, vocational administrative assistant
kim.rosebaum@delautism.org
Bus: 302.224.6020 Ext. 214

What I wish every parent knew Continued from p. 1

have Delaware Medicaid with the MCO.

Medicaid is the “payer of last resort.” In other words, Medicaid pays last if the Medicaid client has other insurance.

About coverage

A federal Medicaid component called Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is for all children with Medicaid through the age of 21. These services are approved and paid for even if Medicaid doesn’t typically cover them. For the sake of space, I will not explain further here, but please know that Medicaid should be paying for services your child’s doctor has documented as needed.

If you had Medicaid coverage through age 18 and switch over to adult Medicaid, you are still covered by federal law for EPSDT benefits. These include dental and vision. And even though a person is on adult Medicaid, he or she is still entitled to the services that fall under EPSDT until his or her 21st birthday.

Do not pay any bill you receive from a provider of Medicaid-approved services—

If you received services from an in-network provider (such as a doctor, therapist, lab, or medical supplies vendor), the provider may not bill you the difference between the charge and what Medicaid has paid. Call the provider that sent the bill, and say you have Medicaid. If the provider does not tell you to ignore the bill, call your MCO about the bill and ask how to proceed.

About co-pays and medication

Children covered under Medicaid have their prescriptions paid for, and there is no co-pay.

Adults covered under Medicaid have co-pays but are not to pay more than \$15 per month in co-pays regardless of how many prescriptions have been filled.

If you ever run out of a medication and can’t reach the doctor, ask the pharmacist to give you three days’ worth of medicine. If you are told “no,” let the pharmacist know that all Delaware pharmacies, which are Medicaid providers, are required to follow this policy.

About communication and case managers

Open and read all mail from your MCO and the state Medicaid office. This is the way they communicate and will include notices of termination if you don’t reply by a certain date.

Anyone receiving Medicaid through long-term care can and should have a case manager from the MCO. If you don’t have a case manager, call the number listed on your mem-

bers’ handbook, which you should have received when you enrolled. If not, request a case manager. (Speaking of members’ handbooks: If the one you have is old, call and request the current handbook.)

If you can’t reach a case manager, your MCO has a member advocate who you should contact.

About the health-care changes

Since the implementation of the Affordable Care Act, many changes have taken place in our health-care systems. The federal agency that oversees Medicare and Medicaid is CMS, which stands for Centers for Medicare & Medicaid Services. With more people living in the community instead of institutions, CMS has been taking a much-needed closer look at many policies that have been in place for many years and modernizing regulations to align with the many changes in the way we live, work, and receive our health services.

In some cases, the rules and policies are changing at a state level as well as at a federal level, so don’t go by something you heard a year ago or even longer. Requirements can change and so can what is and is not covered. It never hurts to ask.

About denials

Because so many changes are in the works, don’t assume that your insurance company is up to date on all of them. A verbal “no” is not good enough; you must receive the denial in writing. And your services cannot be stopped until you have been notified officially on paper.

Denials are automatic, and the insurance company counts on you not to appeal. Once you receive a written denial, start the appeal process. *Always appeal a denial.*

For answers and help

The Community Legal Aid Society, Inc., Disabilities Law Program issued a two-pager about your rights and how to appeal a denial: *How to manage your Delaware managed care organization*. For a copy, visit http://www.delawarefamilytofamily.org/wp-content/uploads/2013/03/April_ManageMCO_Flyer.pdf. Or call (302) 575-0690 in New Castle Co., (302) 674-8503 in Kent Co., or (302) 856-3742 in Sussex Co.

Or call the Delaware Family Voices numbers listed below.

Did you know?

Medicaid pays for diapers (for adults as well as for children over four years old).

Before you pay out of pocket for supplies and equipment, check to see what Medicaid covers.

Toll-free calls about MCO services

Delaware Family Voices® offers a toll-free call about MCO (managed-care organization) services that is open to the public and a great way to learn about Medicaid and its policies. You can also share your concerns, ask

questions, and talk about issues related to Medicaid services and how to access these services. For details, visit www.delawarefamilytofamily.org, search for Manage MCO Call-In, and click on the most current month.

Delaware Family Voices

www.defv.org

(302) 669-3030

(877) 235-3588

For assistance in Spanish, call (302) 669-3033.

INSIDE AutismTM Delaware

Fun for all at summer day camp

Specially designed for youth on the spectrum, Autism Delaware's summer day camp took place August 22–25 this year at the Children's Beach House in Lewes. The annual program applies the challenge-by-choice approach: Children are encouraged to try new activities—and never forced.

Thank you, Lighthouse Church!

A huge thank-you goes out to the Vacation Bible School group at LifeHouse Church and the children's director, Leticia Britton, for donating camp decorations, posters, and camper goodie bags and T-shirts. "Our campers enjoyed tie-dyeing the tees and getting them signed by their fellow campers," says Autism Delaware family service coordinator Dafne Carnright. "And their parents commented on how much their children enjoyed the goodie bags!"

"Our camp program is structured to meet the needs of our kids with a repeating schedule each day," notes Autism Delaware family service coordinator Dafne Carnright. Day camp staff comprises professionals with experience working with youth on the spectrum, such as Delaware Autism Program therapists, teachers, and paraprofessionals.

"Campers remain with the same group for the week," adds Carnright, "rotating through fun activities, such as arts and crafts, a low ropes course, sports activities, swimming in the pool and at the beach, as well as beach activities, like sailing, kayaking, or paddleboarding."

For more information about autism programs, visit autismdelaware.org.

2016 beach picnic

Summer fun for the whole family

Autism Delaware hosted its annual beach picnic on August 28 this year in Cape Henlopen State Park. All families affected by autism statewide were invited to enjoy an early afternoon of fun in the sun. The only cost of admission was a side dish or dessert to share.

For more information about Autism Delaware and family support and outings, visit autismdelaware.org.



Wrap-up of legislative session and prep for the next

The four bills described below were passed during the 2016 legislative session and may affect you and your family. To read the bills in their entirety, visit legis.delaware.gov.

SB93 establishes the Delaware Network for Excellence in Autism. For more information, see the article in this issue on page 5, "Autism network a go!"

SB230 grants "supported decision making." In other words, an adult with an intellectual disability can appoint a helper who can be consulted when important life decisions need to be made.

SB180 grants an "education decision maker." In other words, an adult (18 years of age or older) can get help making decisions about his or her education by consulting a self-appointed educational advocate.

SB221 gives a tax credit to an organization that hires individuals with disabilities. This credit will be applied to the organization's state tax and shall equal 10 percent (but not exceed \$1,500) of the gross wages paid to the individual during his or her first year of employment.

Autism Delaware's policy and community outreach director, Alex Eldreth, will assume a regular schedule of attendance in

the Delaware State Legislature when it returns to session in January 2017, but for now is busy expanding the grassroots group of autism advocates across the state.

"I look forward to adding to our ranks," notes Eldreth. "Did you know that advocacy can be as quick and simple as making a phone call or sending an email? The goal is to give you the opportunity to tell your story and explain your everyday needs and challenges to your elected legislators."

For more information about becoming an autism advocate or about the aforementioned bills, send an email of interest to alex.eldreth@delautism.org. Or call (302) 224-6020.



Del. Rep. Kim Williams (D-Dist. 19) greeted autism advocates from Magnolia Girl Scout Troop 1027 during Autism Delaware's Smart Cookie Day in Legislative Hall in April.

Scholarships awarded

The winners of this year's Autism Delaware Daniel and Lois Gray Memorial Scholarship and the Autism Delaware Adults with Autism Scholarship are as follows:

- Undergraduate Rachel Braitman is majoring in cognitive science with a minor in Spanish and disabilities studies.
- Undergraduate student Natalie Gano is majoring in elementary education with a concentration in special education and a minor in disabilities studies.
- Graduate student Cory Gilden is researching human development and family studies in the college of education and human development.
- Spencer Haber is matriculated in UD's Career & Life Studies Certificate (CLSC) program.
- Senior Tess Hanley is majoring in cognitive science with a minor in disabilities studies and psychology.
- Graduate student Nicole Jones is researching early childhood education, exceptional children and youth, concentrating on autism and severe disabilities.
- Senior Rebecca Lusk is majoring in elementary education and minoring in disabilities studies and dance.
- Gunner Shilling is matriculated in UD's CLSC program.

Visit autismdelaware.org for more information about Autism Delaware scholarships.

The University of Delaware's Career & Life Studies Certificate (CLSC) is a two-year certificate program for students with intellectual disabilities. CLSC provides integrated academic, career or technical, and independent living instruction in preparation for gainful employment. CLSC students attend classes, participate in internships and work experiences, and engage in all aspects of campus life.

For more information, call Brian Freedman at (302) 831-4688.

2016 Tidewater Utilities Charity Golf Outing Funds raised at fun Heritage Shores event

Tidewater Utilities has been sponsoring an annual charity golf outing in Bridgeville since 2008. The purpose is to help give back to the community by partnering with local nonprofits.



Photos by Frank Shade

This year's event, held on August 8, raised more than \$22,000 for Autism Delaware's much-needed programs and services statewide. "This is our most-successful [third-party] event yet!" notes Autism Delaware development director David Woods. "Thank you, Tidewater!"

Special thanks also go to Autism Delaware board member John Willey and Peninsula Oil for putting together three foursomes for the event.

If you would like help putting together a fundraising event, please contact David Woods at (302) 224-6020, ext. 206.

Autism network a go!

Autism Delaware is proud to have been a part of the wide collaborative that worked to establish the Delaware Network for Excellence in Autism (DNEA). And we'll be proud to continue to be a part of it as it gets up and working in the coming year.

The DNEA began with the passage of Senate Bill 93, sponsored by Del. Senator Margaret Rose Henry (D-Dist. 2) and Del. Representative Earl G. Jaques (D-Dist. 27). Then, Governor Jack Markell included start-up funding for DNEA in his budget, and the state legislature passed SB93 and maintained the funding through the budget process. The governor signed SB93 into law this September.

The DNEA's goal is to help provide training and technical assistance for Delaware professionals serving individuals with autism in our state. The DNEA will be housed at the University of Delaware's Center for Disabilities Studies.

If you have questions, contact Teresa Avery at teresa.avery@delautism.org or Alex Eldreth at alex.eldreth@delautism.org.

View the DNEA video on youtube: Visit www.youtube.com, and search for Delaware Network for Excellence in Autism.

Many thanks!

To all the family advocates who worked tirelessly on the DNEA project, including those who wrote letters, participated in Smart Cookie Day, presented at events, and attended commission, joint finance, legislative committee, education, and individual meetings with legislators.

INSIDE Autism™
Delaware

Programs

October

3 or 5; 10 or 12—Junior golf. The Rookery South Golf Course. Milton. **For questions**, call Gail Hecky at (302) 644-3410.

18, 25—Lego club. Autism Delaware Newark office. 6:30–7:30PM. **Register:** Heidi Mizell at (302) 224-6020.

5—Parent coffee hour. Sleep Inn. Breakfast room. Route 1. Lewes. 9:00AM. **R.S.V.P. appreciated but not required:** dafne.carnright@delautism.org.

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

6—Bounce night. Hopping Good Time. 23 Cochran Dr. Building 6. Camden. 5:30–7:30PM. **R.S.V.P.:** Gail Hecky at (302) 644-3410.

8—Sensory friendly movie: *Miss Peregrine’s Home for Peculiar Children*. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

11—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00PM. **R.S.V.P.:** Heidi Mizell at (302) 224-6020.

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

15—Sensory friendly movie: *Storks*. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.

17—Grandparents support group. Autism Delaware Newark office. 6:30PM. **R.S.V.P.:** Heidi Mizell at (302) 224-6020.

21—Haunted-but-not-scary train ride. Wilmington & Western Railroad. 2201 Newport Gap Pike. Wilmington. 6:00PM. **Register:** Kris Grant at (302) 224-6020.

22—Fall festival. Killens Pond State Park. Pavilion 1. Felton. 12:00noon–3:00PM.

Register: Gail Hecky at (302) 644-3410.

November

1, 8, 15—Lego club. Autism Delaware Newark office. 6:30–7:30PM. **Register:** Heidi Mizell at (302) 224-6020.

2, 9, 16, 23, 30—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. **Register:** Karen. Tuohy@redclay.k12.de.us.

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

10—Bounce night. Hopping Good Time. 23 Cochran Dr. Building 6. Camden. 5:30–7:30PM. **R.S.V.P.:** Gail Hecky at (302) 644-3410.

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

19—Sensory friendly movie: *Trolls*. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.

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

December

3—Sensory friendly roller skating. Christiana Skating Center. 801 Christiana Rd. Newark. 5:15–7:15PM.

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

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

— Bounce night. Hopping Good Time. 23 Cochran Dr. Building 6. Camden. 5:30–7:30PM. **R.S.V.P.:** Gail Hecky at (302) 644-3410.

17—Sensory friendly movie: TBD. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.

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

Save the date!

Santa’s little helpers are running around like crazy, all to organize this year’s Autism Delaware holiday parties!

So far—

- **Kent and Sussex Counties holiday party December 10, 12:00noon–3:00PM, in Georgetown**
- **The New Castle County holiday party is still in progress!**

See finalized dates, times, and locations at autismdelaware.org.



PARENT 2 PARENT Written by parents for parents

Every phase of our kids' lives comes with its own set of worries and concerns. I remember when my boys were born that I worried about their eating, sleeping, and "diaper activities." Those beginner worries moved on to sitting, crawling, walking, and electrical outlets. I realized I had two major jobs: "Love them, and keep them alive. Got it!"

As my sons grew, the worries changed again, this time to schools, buses, IEPs (individual education programs), baseball games, and homework. Frankie's independence was ramping up as Jake's special needs grew greater. Today, Frankie is in college, Jake just turned 18—and my head is spinning! How I long for the sippy cup-nap problems.

To meet Jake's needs, I paid attention to all the transition information, reading each memo and asking questions at IEPs. For many school years, I was able to let Jake's teams lead the way. They knew what appropriate goals were next and how to make these goals happen. My input was needed and welcomed, but I relied on their expertise.

As the high school years began, I felt the reins being slowly handed over to me. Now, it's my job to research Jake's options for after his graduation. Provider fairs, site visits, and asking other parents are some ways I gather this information.

One of the decisions we made as a family was applying for guardianship of Jake. As an 18 year old, he can legally make his own health-care and financial decisions; however, we know that Jake does not have the understanding to make good choices, so we are being appointed as his legal guardians. To this end, a series of forms needs to be filled out and notarized, and his doctor must do the same.

As his legal guardians, we must account for his finances to the court every year. If I let this process get to me, it can be another glaring reminder of Jake's special needs, but I am



Special Olympian Jake Nardo

trying not to read too much into it: "Just more forms to fill out. That's all!"

The next big step to tackle is Jake's Social Security. Again, I attended some meetings, asked lots of questions, and now know that I can apply online on Jake's behalf. I also know that the application requires a lot of time and a lot of documents. To be perfectly honest, I have put off the process because I built it up in my mind as insurmountable. But now, it's time to get the hiking boots on, and climb this mountain!

The biggest worry I have is for Jake's long-term care. Where will Jake live? Will his caretakers ever know him like his family does? Will they ever be able to meet all his needs and calm the meltdowns like his family can? Will caretakers love him and treat him like family? My tears start flowing when I really let myself imagine what life will be like when Jake is in a group home and not living at home anymore.

Through the years, my husband and I pointed out to our sons that they are and always will be brothers. We raised Frankie to know that we don't expect Jake to live with him full time, but if Frankie chooses to do so, it will be big brother's decision alone—No influence from us! Whatever Frankie's decision, he must always maintain family tradition. Dinners, vacations, movies, and the like are all required with his brother.

This summer, Jake will attend camp at Easter Seals Camp Fairlee. The time apart from his family will be good experience for us both as we move through these new, uncharted waters of Jake's adulthood. Also, I have a list of books to read about adulthood on the spectrum, and a lot of decisions need to be made. My plan is to keep my own anxiety in check by taking each step as it needs to be taken.

Good luck to all of you going through the same phase I am!

—**Jan Nardo**

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.

Mark your calendar
2017 Walk for Autism
April 1 in Cape Henlopen State Park
April 8 in Fox Point State Park
For details, visit autismdelaware.org.

Put your team together today!

Sun contributor Liz Carlisle is a professional writer-editor as well as the current administrative assistant and much-appreciated right-hand to Autism Delaware's executive director.

A look at SSI benefits

In researching the Social Security Administration (SSA) and Social Security Income (SSI) for this article, much was gleaned from four Delaware parents who have navigated the system and whose adult children are now receiving SSI benefits. Kathy Snyder and Karen Tuohy faced varying levels of challenge in the course of applying for and maintaining SSI benefits for their children. And Lucy and Dave Graham found the process fairly straightforward, and their SSA representative was very helpful.

In addition to sharing their stories, all four parents suggested some must-do's if you, too, are a parent seeking SSI benefits for your child on the autism spectrum.

Do your homework

To navigate the SSA system successfully, do your homework, begins Wilmington parent Dave Graham about his experience when applying for SSI for his son Nick 11 years ago. And pay attention to detail so you know what to expect.

"Start by visiting the SSA website," adds Nick's mother, Lucy Graham, "and following the instructions step by step."

Milford parent Kathy Snyder suggests starting the process early: "My son Austin was diagnosed at age 14," says Snyder, "but I did not apply for his disability until he was almost 16—because I had no clue what to do until I started doing research."

"It's important to get [your child] in the system as soon as it's logical," adds Wilmington parent Karen Tuohy. "It creates a trail of paperwork that has determined the disability. The older your child gets, the harder it is to qualify for a disability, especially with something that a child has had since childhood."

Go in person

You can apply for SSI online at <https://secure.ssa.gov/iClaim/dib> or call your local SSA office. But parents recommend that you go in person with your child to the office. Don't call, warns Dave Graham. "Go down to the office, take a number, and get in line."

Have the paperwork in order

Missing paperwork is one of the major causes of delayed SSI application approvals. Because the Grahams didn't have all of the documents they needed, they had

to make more than one visit to the SSA office.

It's important to know that the

When you apply for your child's SSI, be sure to list all of your child's specific behaviors. You want to say more than "My child has autism."

—Heidi Mizell
Autism Delaware
resource coordinator

The documents you may be asked to provide are listed in *Understanding Supplemental Security Living Arrangements—2016 Edition*. For a copy, visit <https://www.ssa.gov/ssi/text-living-ussi.htm>.

SSA requires many documents: Proof of your child's age and citizenship, medical records, whether your child has seen any psychiatrists, psychologists, or a counselor at school, IEPs (individualized education programs), and more. "You even have to prove to them that it's your own child," says Snyder.

Snyder advises parents to start a notebook, keep a copy of everything, and track every phone call and doctor's appointment.

Know what will affect your child's payment

The SSI threshold (or limit) for countable income is \$2,000.

"Countable income" is the single most important factor in determining the amount of an individual's SSI payment. For adult children with autism, countable income includes the following:

- earned income, such as wages and payments
- unearned income, such as Social Security benefits, pensions, state disability payments, interest income, cash from relatives
- in-kind income, such as food or shelter provided for free or less than its fair market value
- deemed income. This SSA term is used "to identify the process of considering another person's income to be your own"

(https://www.ssa.gov/OP_Home/cfr20/416/416-1160.htm). For more information, visit www.ssa.gov.

If an SSI recipient exceeds the \$2,000 limit, SSI payments will be stopped.

Because Medicaid begins as soon as an individual qualifies for SSI, Medicaid will also be lost.

SSA defines "income" as "anything you receive during a calendar month and can use to meet your needs for food or shelter. It may be in cash or in kind. In-kind income is not cash; it is food or shelter or something you can use to get food or shelter...."

"Countable income is the amount left over after:

- eliminating from consideration all items that are not income; and
- applying all appropriate exclusions to the items that are income.

"Countable income is determined on a calendar month basis. It is the amount actually subtracted from the maximum [f]ederal benefit to determine your eligibility and to compute your monthly payment amount" (<https://www.ssa.gov/oact/cola/countable-income.html>).

A look at SSI benefits Continued from p. 8

This area proved the most challenging to most of the parents interviewed for this article. And the loss of Medicaid is the source of greatest anxiety for parents because so many of the services available to their children are funded by Medicaid.

The Grahams learned about “in-kind income” the hard way. Their son’s SSI payment was cut by a third because of the “one-third reduction rule”: SSA “may reduce your Supplemental Security Income (SSI) payment by one-third if you live in another person’s household throughout a month and you do not pay for the food and shelter you get from the household” (<https://www.ssa.gov/ssi/spotlights/spot-one-third-reduction.htm>).

After researching this issue and consulting an attorney, Dave Graham wrote a letter to SSA saying that he was going to start charging his son for rent. The SSA subsequently restored the payment to the original amount.

To cover her son’s expenses, Lucy Graham deposits his checks in an account she refers to as Nick’s “slush fund.” “Don’t set up a separate checking account in your child’s name,” advises Nick’s dad Dave, “because that account will quickly reach the income threshold, and he will lose his benefits.”

Kathy Snyder told SSA up front that she was charging her son rent, so Austin’s payments have not been affected by his housing. But Austin’s employment income fluctuates because he works hourly, and sporadically. So, Snyder remains confused about the maximum amount that Austin can make before he loses his SSI.

Even if an adult child works steadily, parents find it difficult to understand how the earned income affects the SSI check: “I have one child making, say, \$1,000 a month, and she receives \$250. My other child is making \$10, and he receives \$250. How does that make sense?” asks Tuohy.

Here, a visit to an SSA representative is in order because any delay in reporting wages and changes in income reduces the SSI amount. Parents need to seek the answers to their questions, aggressively and early, to protect the child’s benefits.

For more information, visit *Understanding Supplemental Security Living Arrangements—2016 Edition* at <https://www.ssa.gov/ssi/text-living-ussi.htm>.

Know your rights and limitations

As a single parent, Tuohy has custody of her two children on the spectrum. Now 31 and 30, Bridget and Sean were 6 and 7 years old when Karen divorced—and learned that she could apply for their disability benefits. The amount of the payment

is based on the parent’s income, says Tuohy, “and every year their SSI went down as my salary went up.”

On understanding the role of the representative payee—Tuohy struggles with the domain of the “representative payee.” As the party who receives benefit payments on behalf of an individual with autism, the representative payee can be a family member, friend, or a qualified organization, such as Delaware’s Division of Developmental Disabilities Services (DDDS) (<http://www.ssa.gov/payee>).

The DDDS case workers had presented Tuohy with the risks of assuming responsibility for Sean’s room and board. So, on the recommendation of her son Sean’s case manager, Tuohy signed over her rights as representative payee to DDDS. “It seemed like a good idea at the time,” says Tuohy.

But by naming another individual or organization as a representative payee, a parent risks being out of the communication loop. And then, if a problem arises, the parent will be unaware of it.

For example, if your child’s residential provider is over- or undercompensated, only the representative payee will hear about it. And if your child’s SSI payments are cut as a result of overcompensation, only the representative payee will hear about it. The problem could go on for a long time. So, if you decide to name another individual or organization as your child’s representative payee, be sure to stay in touch with your child’s case manager.

As the representative payees for their children, Snyder and Lucy Graham are able to monitor payments as well as address any changes or issues that come up.

Keep asking questions

Snyder believes her son’s case is being treated unfairly and

Benefits are payable to your spouse if he or she “is caring for your child under age 16 or disabled and receiving Social Security benefits. Your spouse would receive these benefits until the child reaches age 16. At that time, the child’s benefits continue, but your spouse’s benefits stop unless he or she is old enough to receive retirement benefits (age 62 or older) or survivor benefits as a widow or widower (age 60)” (<https://www.ssa.gov/planners/disability/dfamily2.html>).

Continued on p. 10

For more information about SSA and SSI

Visit www.SSA.gov for important information that parents with children on the spectrum should know.

For information about the application process, applicant’s rights, eligibility screening, income reporting, and more, visit the *Supplemental Security*

Income Home Page—2016 Edition at <https://www.ssa.gov/ssi/text-understanding-ssi.htm>.

For answers to SSI’s frequently asked questions, visit <https://faq.ssa.gov>, and click on Supplemental Security Income (SSI).

A look at SSI benefits Continued from p. 9

would like the advice of a benefits counselor outside of SSA. She thinks the problems result, in part, from her receiving disability, too; she has to submit both her paychecks and Austin’s to SSA. Their payments, say Snyder, are based on what the two of them earn in a five-year period: “It’s very confusing. I wish there was an agency or individual with whom Austin and I could meet.”

“We all know that people make mistakes,” adds Autism Delaware executive director Teresa Avery, “so a good rule of thumb is to question something that doesn’t make sense or contradicts what you’ve heard from other parents.”



Bridget Tuohy (31), Karen Tuohy, and Sean Tuohy (30)

What’s the difference between SSI and SSDI?

According to disabilitysecrets.com, many people are unaware of the difference between the two disability programs. Basically, Social Security Disability Insurance (SSDI) is funded through a worker’s payroll taxes and paid when the individual is no longer able to work and has accumulated a sufficient number of work credits. And Social Security Income (SSI) is a federal disability benefit for low-income individuals who either have never worked or haven’t earned enough work credits to qualify for SSDI (<http://www.disabilitysecrets.com/page5-13.html#>).

According to the Social Security Administration, SSI is also for people with a lower rate of Social Security and can supplement the difference if certain requirements are met. Applicants for disability in general must be 18 or older and “unable to work because of a medical condition that is expected to last at least 12 months or result in death” (<https://www.ssa.gov/disabilityssi>). The adult disability checklist can be found at <https://www.ssa.gov/hlp/radr/10/ovw001-checklist.pdf>.

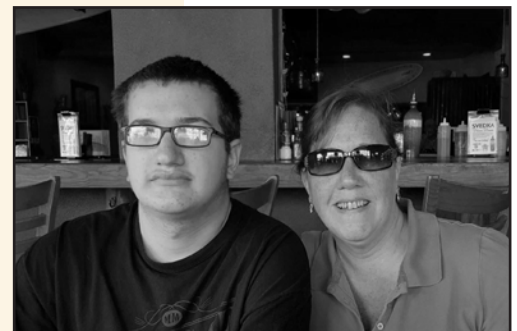
“To be eligible for disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount... is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person’s disability.... For non-blind individuals, the monthly SGA amount for 2016 is \$1130” (<https://www.ssa.gov/OACT/COLA/sga.html>).

Social Security resource guides

- **SSI**—<https://www.ssa.gov/pubs/EN-05-11000.pdf>
- **Benefits for children with disabilities**—<https://www.ssa.gov/pubs/EN-05-10026.pdf>
- **Disability benefits**—<https://www.ssa.gov/pubs/EN-05-10029.pdf>



Nick Graham (29) and Dave Graham



Austin Snyder (20) and Kathy Snyder

How to start an SSI claim for your child on the autism spectrum

You can start a Social Security Income (SSI) claim one of two ways:

- 1** Apply with the help of an advocate or disability attorney who will provide assistance throughout the process.
For information, call Autism Delaware, a disability attorney, or the Community Legal Aid Society’s Disabilities Law Program.

- 2** Do it yourself by calling or going in person to your local Social Security office. Or apply online.

For details and numbers, see the *Disabilities Approval Guide* at <https://www.disabilityapprovalguide.com/social-security-disability/applying-ssi-ssdi>.

Q&A with a Social Security disability attorney
Benefits for children and adults

What is Social Security disability?

Social Security disability is a federal program that provides cash benefits and health insurance to adults, who are not able to work due to physical or mental limitations, and children with severe functional limitations due to a physical or mental disability.

What are the main types of programs under Social Security disability?

- 1. Social Security Disability Insurance (SSDI)** is a work-history based program for workers with disabilities and their children. There are no financial requirements to apply.
- 2. Supplemental Security Income (SSI)** is a welfare-based program for children with disabilities and adults who, based on their work history, are not eligible for SSDI benefits. A person must qualify financially for SSI. Children's financial eligibility is based on their parents' income, resources, and number of children in the family.

How do I apply for benefits?

For adults (18 and older) on the spectrum, apply either online at www.ssa.gov or in person or by telephone appointment at your local Social Security office.

For children (under 18) on the spectrum, you can only apply in person or via telephone appointment at your local Social Security office.

What information do I need to apply?

Prepare the following list of information:

- medical conditions
- medical providers treating the conditions
- medications
- education
- work history

Do I have to be totally disabled to qualify?

No. You do not have to be 100-percent permanently disabled

to qualify. Any disability can be disabling for Social Security disability purposes as long as the disability (or combination of disabilities) significantly affects a person's health and daily functioning.

How are claims for a person with autism evaluated?

For persons with autism, the Social Security Administration (SSA) will evaluate how a condition affects the person at work, home, or school. Psychiatric evaluations, including psychoeducational evaluations, are very important and can be helpful to a person's claim. For children, SSA will collect information from the child's school and teachers.

What are the benefits of working with an attorney on a Social Security disability claim?

The process of applying for Social Security disability can be long and overwhelming. An attorney can help you

- file a claim,
- file appeals and represent you at a hearing (if necessary),
- communicate with you or your child's doctors and teachers,
- help obtain evidence that will help win your claim, and
- provide you with guidance and reassurance during the disability claim process.

How do I schedule a consultation with a Social Security disability attorney?

A free consultation with a Social Security disability attorney is available at The Law Offices of Doroshow, Pasquale, Krawitz & Bhaya. (See box below for contact info.) Attorneys' fees are paid on a contingency basis only, which means the attorney gets paid only if you or your child is found to have a disability.

Sun contributor
Vanessa L. Kassab, Esq., is a practicing attorney in The Law Offices of Doroshow, Pasquale, Krawitz & Bhaya in Wilmington, Del.

Find the Social Security office nearest you:

<https://secure.ssa.gov/ICON/main.jsp>

Social Security disability attorneys

Vanessa L. Kassab, Esq.
Angela Pinto-Ross, Esq.

Law offices:
Doroshow, Pasquale, Krawitz & Bhaya

Statewide phone number:
(888) 734-6800

Community Legal Aid Society, Inc. Disabilities Law Program

Website:
<http://www.declasi.org/disabilities-law-program/>

Phone numbers:
New Castle Co. —(302) 575-0690
TTY/TDD —(302) 575-0696
Kent Co.—(302) 674-8503 (Also TTY/TDD)
Sussex Co.—(302) 856-3742 (Also TTY/TDD)

SSI benefits Training and consulting

Michael Walling

Email:
wallinginc@aol.com

Address:
P.O. Box 1483
Chadds Ford PA 19317

Website:
<http://www.benefits-training.com>



924 Old Harmony Rd.
Suite 201
Newark DE 19713

Nonprofit Organization

U.S. Postage

PAID

Permit #317

Newark DE

Return service requested



Helping People and Families Affected by Autism

2016 Fall Auction Gala

World Café Live at The Queen
500 North Market St., Wilmington

Disco Inferno

Burning Up the Dance Floor for Autism!

Entertainment:

DJ Josh Grant will spin the vinyl for Autism Delaware's *Lip Sync Battle*—and then you can boogie the night away!

Tickets, donation and sponsorship opportunities:

autismdelaware.org



**Friday,
November 4
6:00–11:00 P.M.**

autismdelaware.org