

The Sun

Newsletter

Spring 2022

Also in this issue

Adulting it all

Did you know that ChristianaCare now provides an individualized primary care team for adults on the spectrum? For more, turn to page 5.

Epilepsy and autism

Epilepsy Foundation of Delaware executive director Valerie "Val" Budischak explains how seizure awareness benefits independent-minded individuals on the spectrum. Turn to page 7.

Introducing...

Best-selling author and nationally known autism activist Kerry Magro joined Autism Delaware's board of directors in January. For more, turn to page 10.



Our mission

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



Flex those self-advocacy muscles!

by Cory Gilden, Ph.D., M.S., M.Ed.

Self-advocacy may seem like a lofty abstract concept, but the concrete skills needed to become a self-advocate can be taught and reinforced over time. Some key components to developing self-advocacy are self-awareness, goal identification, and communication skills.

Self-awareness

A lot of background knowledge is needed for someone to be a strong self-advocate. People with autism spectrum disorder (ASD), for example, need to know about their disability, how it affects their lives, the possible accommodations and services they can receive, and what their rights are in relation to receiving these services.

Self-awareness can begin with school-aged children by talking to them about their

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What is self-advocacy?

Self-advocacy is the ability to speak up for yourself to get what you want and need. The skills necessary for self-advocacy can be developed at any age and ability level.

Self-advocacy has pushed progressive disability policy forward to help promote positive changes for people with disabilities. "Nothing about us without us" has become the mantra for the disability rights movement.

Autism DelawareSM

One statewide phone number
(302) 224-6020

One statewide fax number
(302) 224-6017

Email
delautism@delautism.org

Website
AutismDelaware.org

Office locations

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

Lewes
17517 Nassau Commons Blvd.
Unit 1, Lewes DE 19958

Board officers

President: Brendan O’Neill
brendano668@gmail.com

Vice president: Rodger Pearce
rpearce@megee.co

Secretary: John Fisher Gray
John.F.Gray@dupont.com

Treasurer: Jeff Flanders
jflanders@midcoastbankonline.com

The Sun

Managing editor: Lisa Walenceus

Desktop publisher: Carla Koss

Contributors:

Cory Gilden **Jen Nardo**
Heidi Mizell **Virginia Sticinski**

If you prefer to be removed from *The Sun’s* mailing list, please call or mail a request to the Newark office (noted above) or email your request to carla.koss@delautism.org.

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A seat at the table

The theme of this issue of *The Sun* is self-advocacy. To me, self-advocacy means “having a seat at the table and joining others in the meal.”

For years, I have encouraged self-advocates to seek more than awareness—to be active contributors to the change process. Where self-advocates and advocates don’t always agree, sharing their messages ensures a greater understanding of the complexities at work in both successes and challenges.

For a self-advocate, your decisions can focus on opportunities to learn, grow, and live a full life as an included and valued member of your community. Because of your individualized needs and wants, a one-size-fits-all program or platform may not work for you. Therefore, you may find yourself needing and seeking accommodations where none had existed in the past—like an extra seat at the table for someone to help you voice your needs and the needs of your community.

Speaking of accommodations, I heard a story the other day that illustrates the positive change that self-advocacy can affect. It has to do with services—and as you probably know by now, I’m all about connecting folks with whatever can help them achieve their goals. (Sometimes, it’s an organization or service; sometimes, the support can be sitting next to you on the couch.)

Charmaine Smith Wright, M.D., MSHP, relayed the anecdote as an example of the type of service being offered by the Center for Special Health Care Needs

at Christiana-Care. Learn more on page 5, but for now, let me say that the anecdote involves two brothers with autism spectrum disorder (ASD). One is verbal and works a job outside the home, and the other is nonverbal and experiences meltdowns. The Center is guiding the verbal brother on how to act as an attendant for his nonverbal brother. Not only is the attendant-brother honing his self-directing skills and increasing his sense of self-worth, but his nonverbal brother is relying on a trusted family member and, in turn, requiring less anxiety medication. In other words, the brothers are learning to sit at the table and advocate for their needs.

In this issue of *The Sun*, coverage of the Center for Special Health Care Needs includes more about the brothers as well as an overview of the Center’s focus on guiding patients through the transition to adult health care. Accompanying this piece is an overview of Nemours Self-Management’s Division of Transition Care, which helps children learn how to advocate for their own health-care needs and begin their transition to adult health care. And Valerie “Val” Budischak, L.C.S.W., shares how the Epilepsy Foundation of



Brian Hall, M.S.W.
Executive Director

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Flex those self-advocacy muscles Continued from p. 1

strengths and areas of need in different environments, including the tools that could help them use their strengths and accommodate their needs.

The first step can be taken at the team meeting for the child's individual education program (IEP). While seated at the table with the other team members, the child can give input on the IEP goals and development. Helping children and adolescents understand what is available to them and how to creatively adapt their environment to improve functioning will teach them how to flex those self-advocacy muscles.

Goal identification

To know what to ask for, people not only need to be self-aware but also to be able to filter through their background knowledge and to develop and prioritize wants, needs, and goals. Honing problem-solving skills, creating pro-con lists, and getting involved in their IEP meetings are ways to strengthen the ability to define wants, needs, and goals. In turn, you can communicate your wants, needs, and goals to others.

Communication skills

Explaining yourself clearly and respectfully is a key element for self-advocates because this skill will help others to be more receptive to your requests.

Teaching communication skills can begin by teaching how to ask for simple things in a clear and direct manner, such as "I want this to eat" or "I want to watch this show." Ways to build communication

skills include role-playing, modeling how to ask for help, creating signals or using graphic organizers, and giving beginning self-advocates conversation starters. Use of frequent and diverse forms of communication can also help self-advocates with autism learn how to share their wants and needs in appropriate ways.

Opportunities for practice

Budding self-advocates need plenty of opportunity to see advocacy in action and to practice flexing their self-advocacy muscles frequently. In addition to direct instruction on how to self-advocate, children and young adults can observe how their parents and caregivers participate in the IEP team meetings. Or the child or young adult can talk with other professionals who can serve as models on how to conduct themselves.

Parents and educators can also point out when an individual's peers self-advocate as well as positively reinforce the individual's self-advocacy efforts.

Frequent check-ins with people learning how to self-advocate are also necessary to ensure understanding and cultivate skills.

Self-advocacy is a lifelong skill that needs to be prioritized and strengthened regardless of age or ability. Empowering children and adults with ASD to speak up for their needs and rights not only will improve their lives but also is critical to advancing the well-being of people with disabilities overall.

Sources

<https://www.ldatschool.ca/self-determination-and-self-advocacy/>

<https://autisticadvocacy.org/actioncenter/issues/choices/>

<https://www.autismspeaks.org/tool-kit-excerpt/teaching-your-child-self-advocacy>

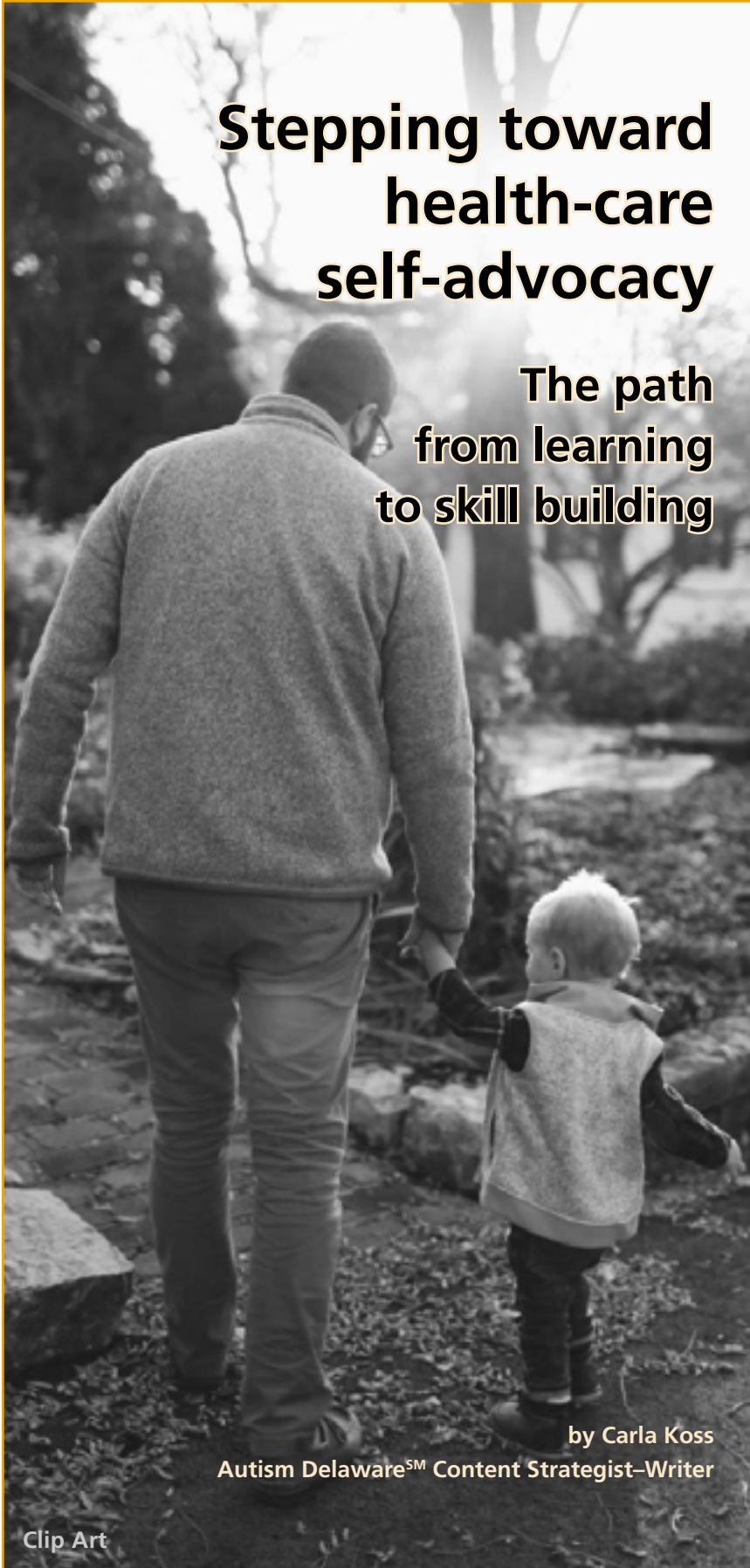
Why is self-advocacy important?

by Cory Gilden, Ph.D.

Self-advocacy is an important component to developing independence and self-determination. The Autistic Self Advocacy Network (ASAN) describes self-determination as having choice in your life and knowing that you have the right to live with dignity and participate in society in a meaningful way.

Also, self-determination has been associated with a better quality of life and positive outcomes for adults with disabilities, such as better employment, independent living, and a higher likelihood of being included in the community.

Sun contributor Cory Gilden is the research and evaluation manager for the National Leadership Consortium on Developmental Disabilities as well as the parent of a son with autism spectrum disorder (ASD).



Stepping toward health-care self-advocacy

The path from learning to skill building

by Carla Koss

Autism DelawareSM Content Strategist–Writer

Clip Art

Six goals for children with autism spectrum disorder (ASD) to grow up to be as independent as possible were written for the winter 2019 issue of *The Sun* by Cory Ellen Nourie, M.S.S., MLSP. As the transition social work coordinator for Nemours/Alfred I. duPont Hospital for Children at the time, Nourie detailed how to reach these goals:

- Carry your state ID or driver's license with you at all times.
- Also, always carry your health insurance card.
- Learn how to refill your prescriptions.
- Start to take your own medicine.
- Know your medical history.
- Have some basic medical information on you at all times, such as an ID bracelet listing an emergency phone number and your ASD diagnosis.

Nourie also provided an overview for parents so they could help their children through the process. (Request a copy of this article or the newsletter at carla.koss@delautism.org.)

Because self-advocacy is the theme of this issue of *The Sun*, Nourie's six goals remain applicable; however, a strong self-advocate requires a lot more background knowledge. The Nemours KidsHealth website can guide you toward this knowledge with four separate folders designed for kids, teens, and parents. (Educators have their own folder, too.)

[The kids folder](#) covers a range of topics with age-appropriate language and graphics. Examples include how the body works, staying healthy, feelings, and puberty and growing up (<https://kidshealth.org/en/kids/center/htbw-main-page.html>).

[The teens folder](#) also covers a range of topics, but these are more relevant to a teenager. Click on School & Jobs, for example, and a teen will find information about bullying and violence, going to college, driving, good friends, jobs and volunteering, school and study tips (<https://kidshealth.org/en/teens/school-jobs/>).

[The parents folder](#) lists information for caregivers, parents, and parents to be. For

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Stepping toward health-care self-advocacy Continued from p. 4

example, Growth & Development/ Growth presents an overview on what to expect and how to understand a child at each age, from newborn to 21 (<https://kidshealth.org/en/parents/growth/>).

Note: The information in the Growth folder is relative to developmental milestones (what most babies and children can do at a certain age). “These milestones help professionals decide if your child is progressing at a healthy rate, and can help behavioral specialists screen for autism and other neurodevelopmental disorders” (<https://theplaceforchildrenwithautism.com/autism-blog/measuring-developmental-progress>).

Because children with a developmental disorder, such as ASD, progress at their own pace, they may need more time before taking a prescribed step. For example, the Nemours Children’s Health website suggests that the transition of care from child to adult medical services can begin when a child turns 11 (<https://www.nemours.org/services/transition-of-care.html>), but an 11 year old on the spectrum may need more maturing before being able to take this step.

In this case, parents may use the Growth information to help gauge their children’s strengths and needs at each age. The Centers for Disease Control and Prevention (CDC) also lists developmental milestones at <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>.

Self-care for comorbidities

In addition to learning self-care as an individual with ASD, a child on the spectrum may have to learn how to manage two or more medical conditions (or comorbidities). “ADHD, anxiety, and depression are the most commonly diagnosed comorbidities, with anxiety and depression being particularly important to watch for in older children, as they become more self-aware” (<https://www.chop.edu/news/autism-s-clinical-companions-frequent-comorbidities-asd>).

Furthermore, “[s]ensory issues are common in people with autism. Autistic people can experience both hypersensitivity (over-responsiveness) and hyposensitivity (under-responsive-ness) to a wide range of stimuli....



“If you are an autistic person, you may need to self-advocate for your sensory needs to be met. This starts with learning about your needs so you understand what works and what doesn’t work for you. Then, you can make changes to your environment, try new tools or strategies, or change your routines to better meet your needs” (<https://www.autismspeaks.org/sensory-issues>).

In other words, stepping toward health-care self-advocacy can be as complex as ASD and as unique as each child. Children able to start learning self-care early and to maintain appropriate supports will be ready for the next step.

Adulting it all

“Kids become legal adults at age 18,” writes Cory Nourie in her KidsHealth article entitled *When Your Child Outgrows Pediatric Care*. “Then, they can visit an adult primary care physician (PCP), such as an internal medicine doctor (internist), a general practitioner, or a family medicine doctor.

“It may be a challenge to find a PCP or adult specialist if your child has a rare condition, disability, or pediatric-onset condition (one that develops only in childhood). You’ll want someone comfortable caring for these complex needs” (<https://kidshealth.org/en/parents/adult-care.html>).

With one convenient location at ChristianaCare, the Center for Special Health Care Needs (the Center) can provide an individualized primary care team to help adults (18 and older) learn how to manage complex medical and social conditions that originated in childhood.

Virtual visits are available for down-state patients who sometimes keep their local PCPs and interact with the Center as needed.

The team comprises physicians, nutritionists, and physical therapists, plus any other specialist that a patient may need (such as a neurologist for someone with ASD) and licensed nurse care coordinators who handle the medical side (such as durable medical equipment and prescriptions) (<https://christianacare.org/services/primarycare/center-special-health-care-needs-primary-care/>).

“We offer a holistic approach,” notes the Center’s director,

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Stepping toward health-care self-advocacy Continued from p. 5

Charmaine Smith Wright, M.D., MSHP. “We focus on the patients’ medical needs, their psychological needs, their social needs. The team includes two nurse care coordinators and also two social workers. These are master’s level senior social workers who cover the social determinants of health to help patients through it all.

“This program is unique,” adds Wright. “We’re the only one in the area that offers the holistic approach.”

Skill building

In a Q&A session with *The Sun*, Dr. Wright answered the following questions about the Center’s program and how it supports adults with ASD and their steps toward self-advocacy:

What’s the first thing you tell a new patient concerning how to advocate for his or her own health care?

“It’s about skill building, how to ‘adult’ on your own,” says Wright. “So, I address that person, walk in and say ‘Hello. You are the patient. I’ll ask you the questions from the get-go.’

It’s about skill building, how to adult on your own....

—Charmaine Smith Wright,
M.D., MSHP

“A first meeting often involves others in the room. I’ll ask ‘Mind if I ask them about you?’ ‘Could you introduce them?’ ‘Could I get your permission to include them in the discussion?’

“I’ll also ask the others ‘How’s your health care?’”

What’s the process if the individual doesn’t grasp the information or if a new issue arises, such as the onset of seizures?

“We consider the cognitive ability of the patient—Does he use pictures? Read?—and use different strategies depending on the individual’s management of care,” explains Wright.

If the individual is still unable to grasp the information, caregivers who speak for the patient receive the “Delaware Ages 21 and Older Checklist—Intellec-

tual or Developmental Disability.” This checklist provides links to health and medical care, state services, and other resources.

How do you determine best practice?

“We are developing our own best practice based on what’s known, seen, and studied,” states Wright. “We surveyed our patients about the space they come to for care, and we asked the Center’s Advisory Board to tell us what our families want and need. We use the scientific literature to find out what others have done and metrics to know if we are successful.

“Upon evaluating this data,” continues Wright, “we realize if a new need has come up, and we adjust our programs accordingly. We develop, study, and implement based on data and experience. And we hold ourselves accountable so we can continue to improve and deliver optimal care to our patients.”

For more information about the Center for Special Health Care Needs at ChristianaCare, click [here](#).

One example of the holistic approach

“Today, I saw brothers with autism,” begins Charmaine Smith Wright, M.D., MSHP, the director of the Center for Special Health Care Needs at ChristianaCare. “One of them is support level 1. [We’ll call him *One*.] *One* uses verbal words, has a job. The other, support level 3. [We’ll call him *Three*.] *Three* has no words and is prone to meltdowns.

“*One* acts as a self-directed attendant for *Three*. Through an Easter Seals program, *One* gets paid for this work, supplements his job at ShopRite while improving his socialization skills and self-worth. And *Three* uses less anxiety medication because the family unit works together.

“I see both for weight loss, too,” adds Wright. “*One* saw the nutritionist, and *Three* is helped by *One*—who provides really good care for his brother.”

According to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, autism spectrum disorder (or ASD, for short) is categorized by severity on a scale of one to three, where level 1 refers to the need for support; level 2, substantial support; level 3, very substantial support.

Epilepsy and autism

Depending on the research quoted, one-third to one-half of people on the spectrum also have epilepsy: “Either way,” begins Valerie “Val” Budischak, L.C.S.W., executive director of the [Epilepsy Foundation of Delaware](#), “epilepsy is still a pretty common condition for folks with autism.”

People on the spectrum have also been known to experience their first seizure in adulthood. And seizures may change across an individual’s lifespan.

“To live independently—and by that, I mean the individual is out of the parent’s house and with someone who can help—” explains Budischak, “the individual needs to know if the seizure is focal impaired



or generalized tonic-clonic [formerly known as grand mal]. Both are the result of abnormal electrical activity in the brain, but different results occur. The individual experiencing a focal impaired seizure could be aware of what’s going on and even talk about the part of the brain being affected. But if both sides of the brain are affected—It’s called a generalized onset seizure—the individual can have a loss of consciousness, which is scary because the individual has no control.”

In addition to seizure awareness, Budischak recommends moving toward independence with the transition of care teams at Nemours and ChristianaCare: “Tell the neurologist ‘When I get older, I want more autonomy.’ And ask questions to determine any specific lifestyle issue: *Is an apartment by myself doable? Do I need a roommate? What do I need to stay safe? What about transportation?* If you intend to drive, you’ll need a doctor to sign the DMV form.”

Budischak also suggests relieving some parental anxiety by wearing an Embrace watch. “It will notify someone when you’re having a seizure. It’s the only FDA-approved smartwatch for seizure detection, so it’s covered by Medicaid.” For more information about the Embrace watch, click [here](#).

“At the Epilepsy Foundation,” adds Budischak, “we do a lot of self-advocacy ourselves. We always tell folks to keep a seizure diary: app, paper, or calendar. Include day and time of seizure plus what you were doing, feeling. And take it to your doctor if there’s a pattern to your seizures. The diary is also good as an aid to have something to say when the doctor asks.”

A seat at the table Continued from p. 2

Delaware supports independent-minded individuals with ASD and seizure disorders.

Also in this issue is an article by longtime *Sun* contributor Cory Gilden, Ph.D., on how to teach self-advocacy. In the “Ask a parent” segment, Heather Petit explains what she has learned as an autistic teaching her autistic children how to self-advocate. And last but not least, nationally known author and speaker Kerry Magro, Ed.D., is introduced as the newest member of the Autism DelawareSM Board of Directors.

I trust you’ll find this issue helpful. Let me hear from you at (302) 224-6020, ext. 222.

Self-advocacy resources for your consideration

[Healthy Transitions App](#)

This interactive smartphone application uses videos to teach young adults the skills they need to become more independent.

[Autism Society](#)

Through a network of affiliates across the country, the Rockland, Md.-based Autism Society “connects people to the resources they need through education, advocacy, support, information and referral, and community programming” (<https://autismsociety.org/who-we-are/>).

[Self Advocates Becoming Empowered](#)

This website provides “resources for self-advocacy groups and individuals with disabilities who wish to learn more about self-advocating” (<https://www.sabeusa.org/resources/>).

[LD@School](#)

This Learning Disabilities Association of Ontario project “includes this website as well as the Educators’ Institute. LD@school is dedicated to providing Ontario educators with information, resources and research related to teaching students with learning disabilities” (<https://www.ldatschool.ca/ldschooll/>).

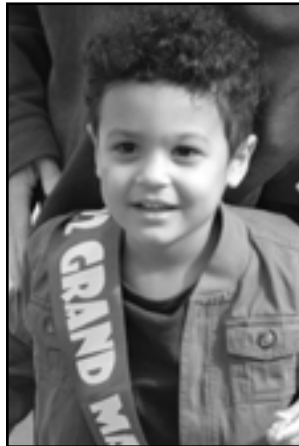
INSIDE AutismSM Delaware

Connecting with other families, vital services, and the community

“We want families to know we are here for them,” begins Autism Delaware director of fund development and engagement David Woods. “We are not just creating a space for them to walk but an opportunity to walk alongside them and with them on their journey with autism.”

“Our 2022 Walk for Autism grand marshals were chosen so that everyone will see a little of themselves and feel comfortable about being engaged.”

This year’s Sussex County Walk grand marshal is Aven Foskey. Last year, the two-year-old led his team in his first-ever Walk for Autism. Called Aven’s Journey, the 17-member team raised almost \$1,500.



“At that Walk,” explains Woods, “Aven and his family connected with Autism Delaware’s family support team. As a result, the Foskey family is now working with a family navigator who is available to answer questions and provide direction as needed—and mom Tanielle and dad Chris have expanded their fundraising to a year-round effort.”

One of the many programs and services supported by Walk is Autism Delaware’s adult services program. Known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short), this program supports Tony Graci in his job at Nemours Children’s Hospital. The 29-year-old is the New Castle County Walk’s grand marshal.



“Having participated every year since the first Walk for Autism,” says Woods, “Tony and his family are key members of an event we like to think of as our family reunion.”

“Plus,” adds Woods, “Tony’s Team raised almost \$14,000 last year for Autism Delaware programs and services. This amount included employer matching gifts.”

“The Walk,” continues Woods, “is Autism Delaware’s largest community event where you can connect with vital programs and services as well as other families in the autism community. We invite all families affected by autism spectrum disorder to join us for this great family event.”



Presented By:



Mark your calendar!

October 8, 2022

**Ft. DuPont State Park
260 Old Elm Ave.
Delaware City**

October 15, 2022

**Hudson Fields
30045 Eagle Crest Rd.
Milton**

Registration opened April 4 and concludes with the event in October.





Sarah McGuire accepts newly created post

Sarah McGuire, M.S., recently accepted the newly created position of Autism Delaware training and quality assurance specialist. With certification from the Health Care Compliance Association, Sarah will also act as the agency's compliance officer.

Sarah is uniquely qualified to assume this new post because of her broad work history at Autism Delaware: In 2010, she began work as a direct support professional (DSP) in Autism Delaware's adult services program known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short). Then, she applied her skill and knowledge to overseeing Autism Delaware's advocacy effort and communications and admin projects. Sarah is also an adjunct instructor in the Human Services graduate program at Wilmington University.

She is currently building a comprehensive quality assurance program that will ensure that Autism Delaware continues to provide essential and effective supports and services to the autism community. Because of her wide-reaching experience and expertise, Sarah plans to work with each Autism Delaware department to build a professional development training program for staff members and to oversee mandated training requirements as well.



Meet Vicky Cromley

As Autism Delaware's new administrative coordinator, Vittoria "Vicky" Cromley brings more than 20 years' experience in customer service to the Newark office's front desk. This experience includes stints with the Wilmington Senior Center, Arden Courts of Wilmington, and the Somerford House and Place of Newark, Delaware.

In her capacity as administrative coordinator, the bilingual Vicky helps facilitate the smooth functioning of the Newark office by providing administrative support to the agency's communications and marketing team and the adult services program known as Productive Opportunities for Work and Recreation (or POW&R, for short). She also manages in-house IT inquiries, tracks paperwork requirements, keeps an inventory of office equipment and supplies, and performs general bookkeeping and administrative tasks.

Lend a hand

Because of the generous hands-on support of volunteers, Autism Delaware events, such as the Walk for Autism, the Drive for Autism, and the Blue Jean Ball, can allocate more of the fundraising dollars to much-needed programs and services, such as family support, adult services, advocacy, and awareness.

Find out how you can become an Autism Delaware volunteer at <https://www.autismdelaware.org/get-involved/volunteer/>. Or contact Autism Delaware's community and volunteer engagement specialist, Susan Campbell, at susan.campbell@delautism.org.

INSIDE AutismSM
DelawareIntroducing
Kerry Magro

Best-selling author, nationally known autism activist, and winner of the 2016 Temple Grandin Award for major achievements



by Lisa Walenceus, Autism Delaware
Communications and Marketing Manager

Kerry Magro, Ed.D., joined Autism Delaware's board of directors in January to serve a three-year term as its newest member. His service to the autism community across Delaware is another step in an autism journey that is dedicated to helping others on the spectrum.

"Most people who meet me don't realize that I didn't speak at all until I was two and a half years old," begins Magro. "For a long time, I didn't even have any sounds. People told my parents I'd grow out of it—Thankfully, my parents didn't believe it."

Magro was diagnosed with pervasive developmental disorder—not otherwise specified (or PDD–NOS, which is now known as autism spectrum disorder, or ASD, for short) at the age of four, after his parents took him to numerous specialists. "That began 15 years of occupational, physical, and speech therapy for me," Magro explains. "Trust me—It wasn't easy."

"While a lot of teens I knew were focused on making friends, getting into relationships, and enjoying after-school activities, I had IEP [individualized education program] meetings, in-house therapists, and doctors' appointments to attend, to help me with things like not being able to speak and having sensory overload and a wide range of other difficulties that I had to deal with."

Magro sees his early experiences, though difficult, as personally satisfying in their results and potentially helpful to people with new ASD diagnoses, but he doesn't want people to see autism just as a diagnosis for children and he doesn't want the autism conversation to be confined to childhood experiences and interventions.

"So much of what you see on TV and in the press is about children. For me, what happens to children with autism when they grow up to be adults with autism is now the big question," says Magro. "It's what's happening today. Kids like me are growing up every single day on the autism spectrum, and we have to be ready for these kids."

(Magro's point is addressed by Autism Delaware's executive director, Brian Hall, and board president, Brendan O'Neill, Esq., in *The big question* on page 11.)

Magro's autism journey—so far

"Because of all my issues and difficulties in childhood," continues Magro, "I really didn't know where I was going to be as an adult. I really didn't have many

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Introducing Kerry Magro Continued from p. 10

aspirations as a kid because of the [number] of services I had to go through.”

Although his aspirations weren't clear in his early years, he has accomplished a great deal, always with an eye toward how he can help others with ASD.

Having earned an undergraduate degree in business administration with a concentration in sports management, a master's degree in strategic communications, and his doctorate in educational technology leadership, Magro has used what he learned to become a nationally recognized autism activist, author, and speaker:

- He has spoken at more than 1,000 events, given two TEDx Talks, and presented for Talks at Google.
- Two of his three books, *Defining Autism From The Heart* and *Autism and Falling in Love*, have reached Amazon best-seller lists for special-needs parenting.
- He also started KFM Making A Difference, a nonprofit organization that hosts inclusion events and gives scholarships to students with ASD to attend college.

He views his work with Autism Delaware as another step in his autism journey.

“The more I've learned about Autism Delaware, the more they've impressed me,” notes Magro. “I'm excited to see what we can do together to provide reliable autism resources across the lifespan for people on the spectrum.”

To learn more about Kerry Magro, visit <https://kerrymagro.com/>.

The library of TEDx Talks can be found at <https://www.ted.com/watch/tedx-talks>.

Talks at Google can be found at <https://talksat.withgoogle.com/>.

The big question

Kerry Magro's most important contribution to Autism Delaware is addressing the big question of an autistic child's readiness for adulthood, notes the agency's executive director, Brian Hall, M.S.W.

“We have always been and will continue to be committed to helping families and parents as they help their children with ASD [autism spectrum disorder],” Hall says. “But we need self-advocates like Dr. Magro to help us make solid decisions about the directions our organization might grow to continue to meet the needs of people with ASD as they make the transition to adulthood and live their lives as adults with autism. He will be an unparalleled resource in that conversation.”

Agreeing with Hall is Brendan O'Neill, Esq., who is president of Autism Delaware's board of directors as well as the recently retired chief defender for the Delaware Office of Defense Services and the father of an adult with ASD.

“Kerry's track record of informed activism and his unique insight from his own experiences as a person with autism will doubtless be an invaluable asset for our board. We are delighted to welcome him to our organization and look forward to working with him to further strengthen our mission to provide support as we look at what lies ahead for people with autism.”

For me, what happens to children with autism when they grow up to be adults with autism is now the big question. It's what's happening today. Kids like me are growing up every single day on the autism spectrum, and we have to be ready for these kids.

—Kerry Magro, Ed.D.

Ask a parent

An autistic parent of four, two of whom are on the autism spectrum, Heather Petit is an associate director in information technology and a ministerial intern pursuing credentialed ministry with a social justice focus on neurodivergence. She personally prefers identity-first language and she/they gender pronouns.



Q *Are you teaching your children how to flex their self-advocacy muscles?*

A As an autistic person and the parent of autistic people, I have been both a self-advocate and a support for someone else's self-advocacy. In both roles, I made plenty of mistakes. As I have learned and grown, I discovered five central truths:

1. There's no shame in having less-common needs. Whether the need is for different software at work or a sensory break during a family outing, autistic needs are human needs. When we treat having human needs as both expected and morally neutral, we make it easier for people to find accommodations. Not being embarrassed that "we need what we need" also makes self-advocacy more comfortable to do.

2. Self-advocacy is about the most-affected person. As a parent, I wanted to make life easier for my kids by acknowledging and meeting their needs, but even as an autistic person, I wasn't always right about how a child was affected and what would help. So, I had to learn how and when to step back and be a support, collaborator, or coach. And by respecting each of my kids' individuality, we came up with better ideas for meeting the need.

3. Just because it didn't work doesn't mean we failed. Even when we're clearly self-advocating, the most important issues

don't get addressed sometimes. But the effort isn't a waste of time—We learn! And we can be proud of ourselves for trying. Self-advocating includes being kind to ourselves and each other and taking time to process and recover, look for new ideas, and try again.

4. We don't have to do it alone. With a proved-trustworthy team to support you, you can get your needs met faster and with less work. My team has made a big difference in my family's life by acting as our guard rails and ramps, early alerts, and cheering section. So, I highly recommend creating a self-advocacy team made up of teachers, special-education team members, therapists, parents, colleagues, bosses, and friends. Your team can also include autistic bloggers and TikTok self-advocates who provide ideas and techniques to try.

5. We can change how we self-advocate. Being a self-advocate can be tiring and difficult, so we need to give ourselves permission to take a break or let someone else handle the work sometimes. Letting ourselves pause when we need to prevents overload and burnout. And sometimes we learn something new we want to try. Changing how we self-advocate works best if we include the idea of changing the plan whenever we need to—right from the start.