

# The Sun

Newsletter

Spring 2021

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## Our mission

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



If you don't know how deeply your life can be affected by a stigma, check out the Centers for Disease Control and Prevention website. As the nation's health protection agency, the CDC defines "stigma" as "discrimination against an identifiable group of people, a place, or a nation" (<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html>). In the article entitled *Reducing Stigma*, the CDC uses, as an example, the current anti-mask stigma perpetrated by Americans who contend COVID-19 is a hoax. But the information in this article can be used by anyone who feels marginalized or bullied—and this includes individuals affected

by autism spectrum disorder (ASD) and their families.

"Stigma hurts everyone by creating more fear or anger toward ordinary people," notes the article. "Stigma can also make people more likely to hide symptoms or illness, keep them from seeking health care immediately, and prevent individuals from adopting healthy behaviors" (<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html>).

**For interactive links to sources and resources, turn to page 4.**

**Makes people more likely to hide symptoms**  
Generally, children and teens with ASD may struggle with their telltale

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## Autism Delaware<sup>SM</sup>

### New!

**One statewide phone number**  
(302) 224-6020

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Autism Delaware, Productive Opportunities for Work and Recreation<sup>SM</sup> and POW&R<sup>SM</sup>, Parent to Parent<sup>SM</sup>, Autism Care Team<sup>SM</sup> and ACT<sup>SM</sup>, and the Autism Delaware puzzle-piece logo are service marks of Autism Delaware Inc.

## Facing the stigma takes an act of courage

If there is one thing I have learned from my years working in the disabilities community, it's that the parents of children with autism spectrum disorder (ASD) exemplify courage. As soon as these parents get out of bed in the morning, they begin the nonstop work of getting their kids' needs met and creating a safe place in the world for them.

Many of these kids have tics or the occasional meltdown in public—behaviors that can be annoying or disturbing to people around them. Even the people who understand that families face unique experiences in raising children on the spectrum may feel put upon in some situations instead of supportive. People will stare at a child with ASD because of his or her behavior. People will also stare because of how the child or parent looks or sounds—things that have nothing to do with their behavior.

While the child may not understand why people are staring, mom and dad sure do. The dread of facing the dirty looks ranks as one of the top reasons families affected by ASD forgo socializing, even though their children need to constantly hone their socialization skills.

Some folks go beyond staring and openly express their disapproval to the parents. That means a child with ASD and other challenges can lose out because his parents are made to feel awful about themselves. Over time, this constant struggle can lead to parents internalizing the guilt and shame about the child's behavior or their parenting

skills. In other words, they feel stigmatized. And getting out of bed every morning and facing the stigma takes an unmitigated act of courage.

In this issue of *The Sun*:

- We look at the stigma of autism and the many ways it affects people and families, including an overview of the concept of "self-stigma."
- For parents who would appreciate knowing how another parent handles the stigma, Autism Delaware cofounder and longtime board member Marcy Kempner describes her experience.
- We also define "ableism," look at how we are unwittingly affected by a cultural preference for "normal," and suggest ways to move past it.
- Following an overview of person-first language and identity-first language, an identity-first advocate addresses whether it lessens the autism stigma.

The stigma issue deserves ongoing discussion. Share your thoughts with me about how you are facing the stigma of autism. Send me an email at [Brian.Hall@delautism.org](mailto:Brian.Hall@delautism.org).

**And remember:** Every day that you face the stigma, you exemplify courage.



**Brian Hall, M.S.W.**  
Executive Director

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**Stigma Continued from p. 1**

traits at the same time their social and sexual awareness awoken. How they cope may depend on where they stand on the spectrum and whether they are girls or boys.

Girls who present less severe symptoms and higher IQs may hide their symptoms so well that they may not be diagnosed at all: "While most every child and adult can relate to the desire to 'fit in' socially, girls who camouflage their autistic traits bring on a completely different set of problems," notes an online article entitled *Do Girls and Women Camouflage Autism* on the Columbia, Md.-based NeuroBehavioral Associates website. "These individuals hide their autism in an effort to achieve greater success at work or in their relationships. This decision is extremely difficult, as consistently hiding a condition like autism is exhausting. People who camouflage their autism may develop anxiety or depression, and experience an overall lower level of life satisfaction. It is through social masking that many girls are not even diagnosed with autism spectrum disorder until they reach adulthood, preventing them from receiving the services and resources that could actually make autism easier to manage.



"Still," continues the article, "the issue isn't as simple as recognizing and diagnosing autism in girls at the same early age as boys. Some women have shared with researchers their concern about being labeled and the negative reactions from others to that label. However, the majority of women expressed that knowing there was a word for their social difference would have allowed them the ability to better understand themselves as well as to access those tools and supports that could have aided them before adulthood" (<https://nbatests.com/do-girls-and-women-camouflage-autism/>).

With the boy's point of view, self-advocate Ryan Lee highlights the need to stop the stigma in his guest post on the Autism Speaks website: "There are...some autistics who aren't totally open to change and know you have to act a certain way in order to be accepted into society. And this can be tough on us. Society can force those of us who are different to hide or 'mask' their autism. That's not how it should work though, at least not in any way that's healthy. When

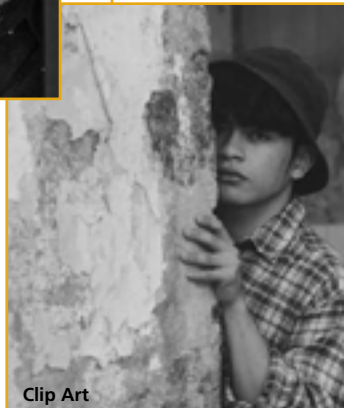
you're accepting to be someone's friend, you should accept and try to understand all aspects of the person.

"We autistics shouldn't feel the need to hide anything," adds Lee in his post. "Some of us may look different or act different, but we still have feelings just like anybody else. For example, I may get a bit irritated when I get interrupted or when someone doesn't let me finish speaking, but that doesn't mean I don't care about people" (<https://www.autismspeaks.org/life-spectrum/its-time-stop-stigma>).

**Keeps people from seeking healthcare and adopting healthy behaviors**

Parenting can be the most difficult relationship we human beings undertake because the relationship changes so dramatically over time, from parent-to-baby to grandparent-to-grandbaby. Generally, we center our lives around the children in our proverbial nests so they grow up to be happy, healthy adults. But when baby is diagnosed with ASD, the nest needs a lot of reinforcement—and the stigma of autism can sometimes undermine the family's foundation.

"In different ways and to different degrees, people in many countries view autism as a source of disappointment, annoyance, shame or worse," writes Marina Sarris in her online article, *The stigma of autism: When all eyes are upon you*. "According to some researchers, stigma may keep families from seeking a diagnosis and services for their children, from participating fully in their communities, and from enjoying the same quality of life as their neighbors. Simply put, stigma influences public health" (<https://www.iancommunity.org/ssc/autism-stigma>).



To influence public health positively, the idea of de-stigmatizing disabilities came with a rethinking of the use of the word "disability." The seeds of change were planted in 1960 with the publication of *Physical Disability—A Psychological Approach*, by the founder and leader of rehabilitation psychology, Beatrice A.

Wright. Because words have power, the focus needed to be put on the person first instead of the disability.

This rethinking evolved into person-first language, and style guides emerged for writing about people with disabilities. One example, produced by the Research and Training Center on Independent Living at the University of Kansas, is currently on its ninth edition. *Guidelines: How to Write about People with Disabilities* explains how to use people-first language accurately so the individual is mentioned first. And it covers a range of disabilities.

**Continued at top of p. 4**

**Stigma** Continued from p. 3

**But has the use of person-first language influenced public health positively?** The answer lies in the willingness of healthcare practitioners to lead by example, write Amy F. Crocker and Susan N. Smith in their paper entitled *Person-first language: are we practicing what we preach?* on the PubMed.gov website: “Person-first language is taught in most health professions programs and mandated by scholarly journals but is often not practiced by healthcare practitioners. The disconnection between academia and clinical practice is significant. Students and new practitioners are often faced with the challenge of holding to their training or falling in line with the status quo. While the use of person-first language should be the norm in all health care settings, unfortunately, often the opposite is true” (<https://pubmed.ncbi.nlm.nih.gov/30799931/>).

Plus, according to an Autism Speaks article entitled *Autism Treatment Network Research on Healthcare Services*, families note difficulty explaining ASD and a child’s specific needs to a busy medical staff (<https://www.autismspeaks.org/resources-medical-needs>). One remedy could be everyone using the same language, but Crocker and Smith stress that more is needed than a change in the words we use: “Health professions educators need to ensure that students understand why this change has taken place and why it is essential. The power language can have not only on patient care but also on patient outcomes is profound and should be understood by both educators and practitioners alike” (<https://pubmed.ncbi.nlm.nih.gov/30799931/>).

While healthcare practitioners may struggle with the use of people-first language, it has become the standard in government documents and scientific journals worldwide, points out Roger Collier in his article entitled *Person-first language: Noble intent but to what effect?* on the National Institutes of Health (NIH) website. “But some people, including members of several disability groups, aren’t big fans of person-first language. They claim it is merely political correctness run amok, verbosity intended to spare hurt feelings yet accomplishing little more than turning one word into two or more words. Even worse, some suggest, tucking the names of diseases and disabilities in the shadows may have the opposite effect of what is intended. It could stigmatize words that were never considered derogatory or pejorative in the first place” (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3519177/>).

Also questioning person-first language, the neurodiversity movement “celebrates autism as a natural variation of the human condition and opposes efforts to cure it. These advocates prefer supports and accommodations for people with ASD, rather than treatments that would erase harmless autistic behaviors” (<https://iancommunity.org/ssc/autism-stigma>). And their language of choice is identity-first. Instead of “child with autism,” they say “autistic child” or “autistic.”

**For a perspective on identity-first language from one Delawarean on the autism spectrum, turn to page 5.**

## Sources and Resources

*Reducing Stigma* on the Centers for Disease Control and Prevention website—<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html>

*Do Girls and Women Camouflage Autism* on the NeuroBehavioral Associates website—<https://nbatests.com/do-girls-and-women-camouflage-autism/>

*It’s time to stop the stigma*, by Ryan Lee, on the Autism Speaks website—<https://www.autismspeaks.org/life-spectrum/its-time-stop-stigma>

*The stigma of autism: When all eyes are upon you*, by Marina Sarris, on the Interactive Autism Network (IAN) website—<https://www.iancommunity.org/ssc/autism-stigma>

*Physical Disability—A Psychological Approach*, by

Beatrice A. Wright, available at Amazon—<https://www.amazon.com/Physical-Disability-Beatrice-Posner-Wright/dp/0060472413>

For more info on *Guidelines: How to Write about People with Disabilities*, by The Research and Training Center on Independent Living—<https://news.ku.edu/research-and-training-center-independent-living-releases-9th-edition-writing-guidelines-0>

*Person-first language: are we practicing what we preach?* by Amy F. Crocker and Susan N. Smith, on the PubMed.gov website—<https://pubmed.ncbi.nlm.nih.gov/30799931/>

*Autism Treatment Network Research on Healthcare Services* on the Autism Speaks website—<https://www.autismspeaks.org/resources-medical-needs>

*Person-first language: Noble intent but to what effect?* by Roger Collier, on the National Institutes of Health (NIH) website—<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3519177/>

# One voice of autism

## “Do you believe that using identity-first language helps to lower the stigma of autism?”

by Heather Petit

For me, switching to identity-first language is not destigmatizing but the natural result of undoing my internalized biases and overcoming a lifetime of masking.

Using person-first language was one way of denying that autism was central to being me. Saying “I’m a person with autism” was me pretending that I could be me and autism could be another thing, like something that came along for the ride: “Hi, I’m Heather, glad to be here; don’t mind the autism.”

It was also about trying to be like other people, because I wanted to be liked and accepted, and excusing the times that “the autism” showed. Only it always showed (even though I’m good at masking). I was ashamed when it showed, when people looked away, excusing it out of politeness, and then distanced themselves from me.

And it was exhausting.

That finally changed when I landed a job where I was welcomed as my whole self and was asked to use my whole unique mind at full power. More, I was accommodated easily and without comment.

I learned how to not mask and how to use my sensory processing and sensory-meshed cognition all over again. In the process, I had to put down all my defenses, stop being embarrassed about my usual functions of stimming, overload, and meltdown. And I made peace with my co-occurring conditions, the faceblindness, dyspraxia, intermittent nonspeaking, connective tissue issues, and more.

In the context of relational safety, I could relax my defenses and put energy into my strengths. When I was able to embrace being me, I felt like I was getting 50 percent more brain power. Being empowered by an accessible and accommodating context, person-first language no longer fit. I became “an autistic person.” And I discovered that, while it’s not always easy being me, I like who I am. I **am** autistic.

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*When I was able to embrace being me, I felt like I was getting 50 percent more brain power. Being empowered by an accessible and accommodating context, person-first language no longer fit. I became “an autistic person.”*

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I’m also a publicly-representing minister-in-formation, and being “autistic” is a matter of justice and equity. I remind people that autistic people exist in every aspect of life. We are children, adults, elders. It’s important that people stop looking away and publicly acknowledge that autistics can be who they are, not put their core selves aside to fit in.

Besides, fitting in is overrated. We can be in each other’s company without having to be alike. The world is big enough to allow room for our differences. In ministry, I have the privilege of leading with my identity when it applies. I may have to tell people in the congregation I serve that I won’t recognize their faces, but nametags work just fine.

It is a compelling aspect of ministry to seek justice and create beloved community where I am not merely tolerated but enthusiastically welcomed.

Finally, it is not empowering to have a way of self-identifying forced on you as a default mode or, worse, as a constant announcement. I don’t lead with my identity when it’s not relevant. It doesn’t have to be the first thing people learn about me all the time; context matters.

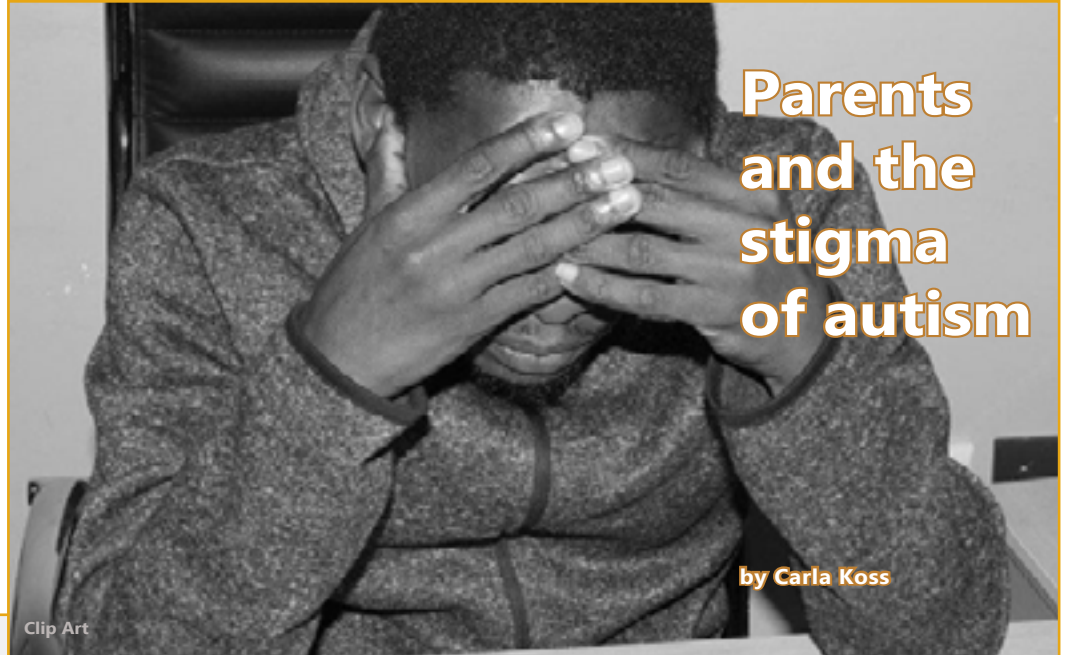
Just like me, my children also choose how they refer to themselves, if and when they mention their neurotype, and whether they use one method in

one context and another method in a different context. Their choice can be fluid, dynamic, what feels safe, comfortable, and true.

Instead of the question you asked, it might prove useful to ask why an individual might use different language. Through this question, we may come to understand the nuance of meaning and consider what that would feel like for ourselves. To allow each person to choose what suits them in any time and place: That is true empowerment!

**An autistic parent of four, two of whom are on the autism spectrum, Sun contributor 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.**

Many parents of children on the autism spectrum, note researchers at the University of Bedfordshire's Institute of Health Research (IHR) in Great Britain, "can feel blamed for their child's behaviour, feel socially excluded and isolated, and suffer from low self-esteem and poor psychological well-being. This increases the risk of experiencing self-stigma which further exacerbates these and other negative consequences" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6390626/>).



## Parents and the stigma of autism

by Carla Koss

Clip Art

Many autism advocates admit that educating the public about autism should increase tolerance and decrease the stigma. But until the world is educated, how does a parent cope?

Check out the Autism Delaware<sup>SM</sup> resource directory for parent training at [AutismDelaware.org/Resource Directory](http://AutismDelaware.org/ResourceDirectory); then scroll down to Parent Training Resources.

Also, watch for Autism Delaware's twice-a-year Parent to Parent<sup>SM</sup> training. In only five weeks, you'll learn how to communicate effectively.

The IHR pilot and feasibility study, entitled *Stigma of living as an autism carer*, also points to the high number of stigma-affected families: "Stigma is prominent in the lives of families with an autistic family member, with up to 95% of families reporting to experience some form of stigma" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6390626/>).

### Defining "self-stigma"

The IHR researchers define self-stigma as "the phenomenon by which the public's negative stereotypes toward both autistic people and, crucially, their family carers, subsequently becomes accepted by parents/carers and incorporated within their own psychological identity...." In other words, individuals and carers are internalizing the negative value judgments.

Recognizing the crucial role that so many parents and caregivers play in the lives of their children on the spectrum, the researchers not only point out the connection between

stigma and a parent's well-being but also "theorise that increasing the resilience to stigma will have a positive impact on their well-being and subsequently their caregiving abilities" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6390626/>).

### Increasing the resilience to stigma

The Centers for Disease Control and Prevention (CDC) offers eight actions that community leaders and public health officials can take to increase resilience. Of particular relevance to the autism community are the four actions listed here:

- // Correcting negative language that can cause stigma by sharing accurate information....
- // Speaking out against negative behaviors and statements....
- // Making sure that images used in communications show diverse communities and do not reinforce stereotypes....
- // Suggesting virtual resources for mental health or other social support services for people who have experienced stigma or discrimination" (<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html>).

**A two-time First State Award winner for writing, Carla Koss has 25 years' experience as a writer-editor in the medical and disabilities fields, has served as managing editor for the Autism Delaware<sup>SM</sup> quarterly newsletter for more than 10 years, and is the agency's current content strategist-writer.**

# Rejecting the stigma

by Marcy Kempner, parent-advocate and Autism Delaware<sup>SM</sup> cofounder

It's an interesting time to consider where we are, as a country, on the subject of disability stigma, as we move away from a president who clearly mocked a reporter with a disability and toward a president who talks openly about his childhood disability and celebrates people working through those challenges. I wish I could say that this new administration means that we have solved all the problems. Unfortunately, I know that not enough has changed. As I reflect on the piece that I wrote 16 years ago (below) about my son, Ethan,

I was in the mall the other day, and a woman told me that my son was being "obstreperous." I had to go home and look up the word just to be sure that I had the right meaning, and sure enough, she was right. Ethan is 10 years old and has autism.

Obstreperous means "noisy and disruptive." Noisy and disruptive often describe people with autism. We work very hard on teaching Ethan to control his behavior in public. At his school, the Delaware Autism Program, they practice going into the community often, usually once or twice a week, because it is so challenging for people with autism to behave the way that "normal" people are expected to behave. The woman who labeled my son admitted that she could tell that he had some kind of disability, but she was still clearly peeved by his behavior. Or maybe she was upset by my inability to control him.

For the record, Ethan loves going to the mall. It's one of his favorite places. He spends most of the time "working," earning pennies on a card for each interval of time that he stays with me and doesn't wander away, eventually earning his reward of being able to browse all the videos at FYE or the Disney store.

I can still remember the pain of being looked down on by a stranger and feeling like she didn't see Ethan as a person of value and importance. I know that I felt anger and frustration then, and that this disrespect still goes on today.

So what do we do? We keep going—little by little—article by article—conversation by conversation! We keep celebrating our loved ones with autism, and tell any and all who will listen that our kids are exceptional and valuable. Let's be like Joe, and raise up others in our community.

He had earned going to FYE, and I was letting him browse away to his heart's content. He was very happy, and I was happy to let him enjoy himself.

He doesn't understand issues of personal space very well and sometimes gets too close to people. He also makes little noises at times, squeaks and raspberries, or says lines from his favorite movies to nobody in particular. It can look odd, but it is not hurting anyone.

It's hard to have to be saying "No" or "Shush" or "Quiet" all the time. Especially when you understand that autism is a neurological disorder.

Physical self-control is a constant struggle for my son. We have even cautiously tried some medications, but so far none have really made a difference. It just takes rolling up your sleeves and realizing that teaching kids with autism is a long, hard process. While they can learn and achieve a great deal, most things take a long time to sink in, and some never really do. And often you have to pick your battles. A little noisy disruption is preferable to having him wander away and losing him. These are the choices you are constantly faced with when you love someone with autism.

I have come to the conclusion that,

We reject—at every turn—the culture of secrecy and shame that, too often, accompanies a diagnosis of any disability. I get so frustrated by confidentiality rules and regulations that imply something to be ashamed of. There is no magic wand to wipe out the ignorance and fear. But collectively, we can change the conversation, elevate the discourse, and educate everyone we come in contact with: Our loved ones with autism are important, valued people who deserve to be accepted and included in the community.

Who's with me?

while I will never give up working with my son to help him overcome his challenges, I hate the idea that I am always trying to shape him to fit into some mold of what is supposed to be normal. I would rather spend time working on the rest of the world and changing their expectations of acceptable behavior.

Two days after our trip to the mall, I watched a terrific movie based on the book by Wilmington writer Rachel Simon called *Riding the Bus with My Sister*. In it, Simon's character struggles with her frustrations in dealing with her sister Beth who is developmentally disabled and, not incidentally, often obstreperous. Only when Rachel gives in and enters Beth's world, literally riding the buses all day, does she begin to appreciate Beth for who she is and realize the positive effect Beth has on the rest of the world. Only then does [Rachel] stop trying to change Beth to fit her idea of acceptable and, instead, accepts her as she is.

What an amazing example. My dream is a world where slightly obstreperous behavior by differently-abled people is not looked down on but rather understood and accepted patiently. My dream is a world that appreciates and values my son, obstreperous behavior and all.

There is more to the definition of “ableism” than “discrimination or prejudice against individuals with disabilities” (<https://www.merriam-webster.com/dictionary/ableism>).

Ableism is also the culturally held belief that “normal” means not being disabled and, therefore, better.

According to Thomas Hehir, director of the School Leadership Program at the Harvard Graduate School of Education, people support ableism when they automatically assume that their children’s participation in the world requires a direction that often undermines them.

One of Hehir’s examples: the parents who wanted their son with a hearing impairment to live as if he were “normal” hearing. They made sure he learned to lip-read, but not to sign, and enrolled him in the neighborhood school—where he struggled because he couldn’t comprehend as quickly as his classmates without hearing impairments.

This exemplifies, notes Hehir in his online article entitled *Confronting Ableism*, “how society’s pervasive negative attitude about disability...often makes the world unwelcoming and inaccessible for people with disabilities. An ableist perspective asserts that it is preferable for a child to read print rather than Braille” (<https://www.learntechlib.org/p/99685/>).

In other words, normal is better.

“At its heart, ableism is rooted in the assumption that disabled people require ‘fixing’ and defines people by their disability,” writes Ashley Eisenmenger, PR coordinator for Access Living, a Chicago-based advocacy for disability rights, and author of the 2019 online article *Ableism 101: What it is, what it looks like, and what we can do to fix it*.

“Like racism and sexism,” continues Eisenmenger in her article, “ableism classifies entire groups of people as ‘less than’ and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities” (<https://www.accessliving.org/newsroom/blog/ableism-101/>).

## Defining “ableism”

Clip Art

by Carla Koss

### How to acknowledge and move past ableism

Noting the successful effort made so far in American schools to acknowledge and move past ableism, Hehir further notes that more work needs to be done: “[E]ducators must recognize and challenge the ableist assumptions that still permeate the culture and guide much special education practice. Students with disabilities need carefully constructed, individual instructional programs that recognize the effects of their disability while creating opportunities for them to learn and fully participate in school and society” (<https://www.learntechlib.org/p/99685/>).

And Eisenmenger suggests the following action plan:

- “ Believe people when they disclose a disability.
- “ Similarly, don’t accuse people of ‘faking’ their disability.
- “ Listen to people when they request an accommodation.
- “ Don’t assume you know what someone needs.
- “ Never touch a person with a disability or their mobility equipment without consent.
- “ Keep invasive questions to yourself.
- “ Don’t speak on behalf of someone with a disability unless they explicitly ask you to.
- “ Talk about disability with children and young people.
- “ Incorporate accessibility into your event planning.
- “ Learn more about being a good disability ally...” (<https://www.accessliving.org/newsroom/blog/ableism-101/>).

#### Consider this resource:

***Disrupting Ableism with Artful Activism*, from the online event series “The Art of Flourishing: Conversations on Disability”—<https://www.thehastings-center.org/disrupting-ableism-with-artful-activism/>**





## April is autism awareness month!

Consider the COVID restrictions as you “Do your thing” to raise awareness safely in your community.

“Join our events, or create your own,” suggests Autism Delaware director of fund development & engagement David Woods, “but do something fun! Call me if you want help coming up with an idea.”

Statewide, the number is (302) 224-6020, ext. 206.



[Bellevue State Park, Wilmington](#)  
[October 16](#)

[Cape Henlopen State Park, Lewes](#)  
[October 23](#)

The 15th Annual Walk for Autism has been designed to meet the current pandemic guidelines set by the CDC (Centers for Disease Control and Prevention), state and federal authorities, and Delaware’s state park system. For example, a virtual walk has been set up for both locations plus three starting times for both in-park walks.

Also, the walks have been moved to October—hopefully safer dates, notes Autism Delaware director of fund development & engagement David Woods: “By moving the Walk for Autism to October, we have a better chance of offering our families the opportunity to come together in community—something they have not been able to do for too long.

“By opening registration now, when many pandemic-related restrictions remain in place,” adds David, “we give our families something to look forward to as well as plenty of time to raise awareness and recruit team members.”

“Please be assured,” continues David, “as the guidelines change, we will adjust accordingly and keep you informed.”

### Registration is now open.

“If you’re asking yourself why we would open registration so early,” says David, “the answer is simple: Because the work of Autism Delaware is ongoing, and the much-needed funds we raise help fuel our mission, helping people and families affected by autism. We need your support to move forward.”

### New!

An event program is being printed for the first time this year. It will highlight the teams, participants, supporters, and sponsors. For the details, click here: <https://autismdelaware.salsalabs.org/walkforautismeventprogram>.

### For more information

- To register for the walk and start or join a team, click on the links in the Walk for Autism banner above.
- To volunteer, click here: [volunteers@delautism.org](mailto:volunteers@delautism.org)
- To purchase a sponsorship, click here: <https://autismdelaware.salsalabs.org/walksponsorshipform>

# INSIDE Autism Delaware

## Family services expanded

Because of families' increased need for support across the state, Autism Delaware's family services expanded its Autism Care Team<sup>SM</sup> Program. Known as the ACT<sup>SM</sup> Program, for short, this service connects a family affected by autism with a trained and highly specialized family support provider (FSP).

Not only is each FSP trained to support the family through its individual autism journey, but each is also the parent or caregiver of an individual on the spectrum. So, each family affected by autism benefits from their FSP's firsthand knowledge of the autism process in Delaware as well as from their FSP's professional guidance.

Autism Delaware's expansion of the ACT Program was made possible through generous grants from Highmark Blue Cross Blue Shield and the Delaware Division of Prevention and Behavioral Health.

The new members of the Autism Care Team in New Castle County are Heather Akridge and Aditi Hirani; in Kent County, Gwen Senato and Condea Sewell; and in Sussex County, Megan O'Bier. Meet them here!



**Heather Akridge:** "I love giving back what was given to me as a mother participating in the early-intervention journey. One of my greatest joys in life is knowing that I have been able to provide families with the skills they need to advocate for their children as well as provide empathetic support."

**Condea Sewell:** "I strive to consistently grow and learn, and value empathy, understanding, and thoughtfulness. One of my favorite quotes, 'Nothing will work unless you do' (Maya Angelou). I will work to provide the best of me to help families within my community."



**Aditi Hirani:** "I am a strong believer in positive thinking and endeavor. I hope to be a reliable support for the families I interact with and also grow as an advocate for them."

**Megan O'Bier:** "A lot of my time is spent taking my son Braxton to and from therapies. I am looking forward to this opportunity [with Autism Delaware] to help other families and to learn as much as I can!"



**Gwen Senato:** "I have worked professionally with children and families as a preschool teacher and kids fitness coach, and have volunteered in many organizations throughout the community. I am passionate about helping people and supporting them in reaching their goals."

**Do you or someone you know need support for a loved one with autism?**  
**Contact Autism Delaware intake coordinator Melanie Matusheski at [referrals@delautism.org](mailto:referrals@delautism.org).**



## A lot of support

The expansive effort noted on page 10 takes a lot of support: Not only are a lot more families looking for the specialized guidance offered by Autism Delaware’s Autism Care Team<sup>SM</sup> Program, but a lot more funds are now needed to support this family service.

The 2020–21 annual fund drive addresses this financial balance. Highlighted in the fund drive’s outreach are the struggles of one Kent County mother and her 10-year-old son with autism—and how working with Autism Delaware family support provider Karen Mackie helped turn their lives around.

As you’ll note on page 10, the Autism Care Team Program is still accepting families in need of guidance and support.

And Autism Delaware is still accepting donations to support them all.

For more about Karen Mackie and the family she helped—and to make a donation to Autism Delaware—visit <https://www.delautism.org/change-the-world/donate/>.

And please be generous.

Thank you.

## Autism Delaware family navigator achieves national certification



Autism Delaware family navigator Tomara Williams is the latest family services staff member to achieve status as a certified family peer specialist<sup>TM</sup> (CFPST<sup>TM</sup>).

In earning this national certification, Tomara had to prove her competency and lived experience as the parent of a child with autism spectrum disorder (ASD), plus complete 88 hours of training and 1,000 hours of peer-level support to other families affected by ASD—as well as pass the national certification exam (<https://www.ffcmh.org/certification/>).

“This national certification not only ensures professional proficiency in Tomara’s work, but also provides her with even more tools for helping our families,” notes Autism Delaware policy & family services director Annalisa Ekbladh, CPSP, CFPS. “It’s quite an achievement.”

## Minnesota Vikings offensive tackle Brian O’Neill raffled off his cleats to benefit Autism Delaware.

The autographed cleats were designed with the autism puzzle piece in honor of his sister, a participant in Autism Delaware’s adult services program known as Productive Opportunities for Work and Recreation<sup>SM</sup>, or POW&R<sup>SM</sup>, for short.

The cleats sold on ebay for \$1,600.

Thank you, Brian!



# INSIDE Autism Delaware



Thursday, May 13, 2021

DuPont Country Club

**Top sponsors:**

- Toyota
- Currency Technics Metrics
- Leaf Filter
- FedEx

Players will start the day with team introductions and a live auction. Then, they will hit the links for an exciting round of golf with a scramble format.

DuPont Country Club food and beer provided by Autism Delaware sponsor N.K.S. Distributors will be available to players all day.

**Put your team together today!**

**Contact the tournament director:**  
[Deanna.Principe@delautism.org](mailto:Deanna.Principe@delautism.org)

*Interested in volunteering?*

Send an email of interest to [volunteers@delautism.org](mailto:volunteers@delautism.org).



## Share your skills and expertise here!

Each issue of Autism Delaware's quarterly newsletter comprises articles on best practice and up-to-date research.

These articles are researched, written, and edited by professionals and parent-advocates who share their writing-editing skills as well as their knowledge and expertise on a range of issues relevant to Delaware's autism community.

If you would like to join them, send an email of interest to *The Sun's* managing editor at [Carla.Koss@delautism.org](mailto:Carla.Koss@delautism.org).

