



THE SUN

SPRING 2024

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

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

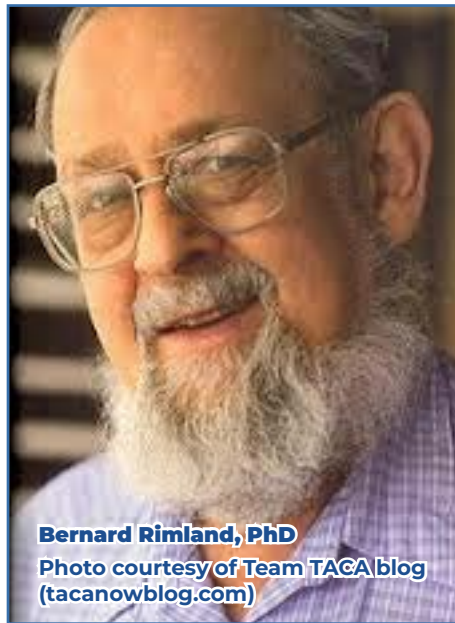
From the need for awareness to the quest for acceptance and inclusion

The first 60 years of autism advocacy

In the 1960s, Bernard Rimland had a home library full of psychology textbooks after earning his doctorate degree. These books came in handy when his son, Mark, began exhibiting behavioral and communication difficulties that several pediatricians were unable to diagnose.^[A]

Why? Because not until 1980 did “autism” appear as an official diagnostic category in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III).^[A]

“Fortunately,” writes Autism Research Institute executive director Stephen Edelson, PhD, in his online article, “Dr. Rimland’s wife remembered reading a psychology textbook that described a child who acted differently than others. They searched through a pile of boxes, found the book, located the story, and realized immediately that their son had autism. This was the first time that Dr. Rimland saw the word ‘autism,’ even though he had completed advanced degrees in psychology just a few years earlier.”^[A]



Bernard Rimland, PhD
Photo courtesy of Team TACA blog (tacanowblog.com)

Armed with an answer, Rimland researched the available literature on autism—and discovered that the parents of a child with behavioral and communication difficulties were assumed to be emotionally and physically neglectful and, therefore, responsible for their child’s autism. As a parent of a son with autism, Rimland began writing a rebuttal—that blossomed into a book on autism diagnosis,

genetics, and cognition. Entitled *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, Rimland’s work was published in 1964.^[A]

Rimland also decided to raise awareness of autism and how children and their families are affected by it.

How? He founded the Autism Society of America (ASA) in 1965 and established the Autism Research Institute in 1967.^[A] And in the early 1970s, Rimland and the ASA set in motion the nationwide autism awareness campaign that the U.S. Congress adopted in 1984.^[B]—and that Autism Delaware celebrates every April.

When the first studies into the prevalence of autism began in the 1960s and ‘70s, the estimated rate was two to four cases of autism per 10,000 children. “This led to the impression that autism was a rare childhood disorder.” But the diagnostic criteria for autism expanded in the late 1980s and ‘90s, so the prevalence studies resulted in “dramatic increases.”^[C]

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- Awareness
- Community engagement
- Fund development

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Drawing the right attention

In April, the public's attention is drawn to autism and the individuals and families affected by it. In Delaware, April had been known as Autism Awareness Month, but we now celebrate [Autism Acceptance and Inclusion Month](#). For some background on this shift, check out this issue's cover story.

Historically, April also featured [Smart Cookie Day](#), the one day of the year that we directed the attention of our elected officials to the needs of individuals and families affected by autism. This year, however, Smart Cookie Day happened early. On March 27, we all journeyed to Legislative Hall in Dover to kick off a month of advocacy.

This annual trek puts us face to face with our elected officials. Not only do we tell our personal stories, but we also explain the specific needs of our loved ones on the spectrum as well as the needs of our families. Plus, we get to suggest how our state representatives might help. This interaction may sound scary, but advocates report a great sense of satisfaction and hope after talking to their representatives.

We also get to say "thank you" for any legislation they have written or helped to pass. For supporting specific issues, we call our legislators "smart cookies" and hand-deliver mouth-watering handmade cookies. The response

is always a big smile.

After our program in Leg Hall, we join the governor in his or her office. There, he or she signs a proclamation noting April as Autism

Acceptance and Inclusion Month in Delaware. Many self- and parent-advocates again share their stories in the hope of convincing the governor to advocate for needed legislation.

The process for enacting legislation into law usually takes years. So, each [autism advocate](#) must practice determination and patience. The "touchdown" happens when the legislation created by our state representatives is signed into law by the governor.

Whether you are a self-advocate or a parent-advocate, you are never alone in this process. Autism Delaware's staff will train you in how to, for example, shake hands with the governor and remain at your side while you share your story. In fact, you'll have an entire room full of fellow advocates for support. With an autism prevalence rate of one in 36, there are a lot more of us every day.



Brian Hall, MSW
Executive Director

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The first 60 years of autism advocacy Continued from p. 1

In turn, an updated DSM was “developed with a great deal of input from mental health professionals and professional organizations.”^[E] The diagnoses included classic autism, Asperger’s syndrome, and pervasive developmental disorder—not otherwise specified (PDD–NOS). DSM-IV was published in 1994.^[E]

Autism awareness expands with the next generation

Yet by 1997, when Marcy Kempner’s son, Ethan, was diagnosed, autism was still a little-known disorder: “It was considered quite rare, and no one knew exactly what caused it,” notes Kempner, who is an Autism DelawareSM founder and currently serves on the board.

“The next year,” says Kempner, “when we first started the Autism Society of Delaware [or ASD, a branch of the ASA], I knew that raising awareness would be a key part of being able to do anything else. Being able to raise awareness about the challenges, the lack of services, and the need for better research and understanding was vital to being able to make progress. And I always knew that it would be so important for Ethan’s life to have the rest of the world able to understand him and even, dare I say, appreciate him. More public awareness would truly impact his life.

“I have a background in television and media,” adds Ethan’s mom, who also works as a freelance sports television producer–director, “so I feel like I was particularly tuned into the need for visibility and publicity. I tried to bring my knowledge and expertise to all that we did back then to help raise awareness. We did billboard campaigns, TV and radio spots, other media, including the fledgling world of websites—There was no social media yet!”

Then in April 1999, Delaware Governor Tom Carper and Lieutenant Governor Ruth Ann Minner first proclaimed April as the state’s month for autism awareness. Kempner joined other ASD parent-advocates in witnessing the event.

“Having the governor and state legislature recognize Autism Awareness Month when we were just getting started made a huge difference to us,” says Kempner. “We felt like we were making things happen!”

“Twenty-five years later, seeing Gov. John Carney recognize us, knowing how much progress we’ve made and how much understanding and knowledge of autism has changed in the wider world over the years, it all feels like a great acknowledgment of all the hard work.”

By 2008, the autism prevalence rate had risen to one in 88 children.^[E] According to a reexamination of the diagnostic data from an autism prevalence study made about 30 years earlier, “[u]nderstanding the extent to which this reflects changes in awareness and clinical practice and/or a true increase in the incidence of the disorder has important clinical and research implications.”^[E] So, raising autism awareness remained crucial to the community.

“I know,” adds Kempner, “that we still have plenty of work to do. Awareness has led to better



Artie Kempner introduced his son, Ethan, to Gov. Tom Carper at Delaware’s first Autism Awareness Month.

understanding, which has led to more opportunities, which has led to increased acceptance and inclusion. So, we need to always keep pushing that awareness!”

Another generation finds its voice

As we all know, autism’s effect on an individual depends on where he or she stands on the spectrum. Likewise, an autistic’s voice is as unique. And when the neurodiversity movement began gaining momentum in the 1990s, autistics began speaking their minds with messages that range from strong to gentle: “Neurodiversity as a social justice and civil rights movement intersects with the wider disability rights movement,” notes researcher Kathy Leadbitter and her team in their findings published in *Frontiers in Psychology*. “The most significant premise of both is that disability is not simply a defect in the individual, but arises from the interaction between a non-standard individual and an unaccommodating environment. Consistent with this stance, many neurodiversity proponents do

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Self-advocacy advice from a high schooler with autism

by Cory Gilden, PhD

In this question-and-answer session, Cory Gilden interviews her 15-year-old son Casey. A tenth-grader at Thomas McKean High School in the Red Clay School District, Casey has been attending his IEP (individualized education program) meetings since he was in middle school and learning how to advocate for himself in the IEP process and in school in general.

Q: *How would you define "advocacy"?*

A: "It means to stand up for yourself."

Q: *How do you advocate for yourself in school?*

A: "I advocate by asking for help and asking for when I need to take a break."

Q: *How did you learn to advocate for yourself?*

A: "I learned from my parents."

Q: *How do you advocate for yourself in your IEP meetings?*

A: "I pay attention and ask questions about certain things. You tell your teachers how you're doing and how they can help you. It's really about what I need."

Q: *How do you prepare for an IEP?*

A: "I talk with my mom before the IEP meeting about what

A cont'd:

we should say at the meeting and any questions I have."

Q: *How do you know the IEP team is listening to you?*

A: "They look at me and talk about me."

Q: *Why is it important to advocate for yourself?*

A: "Because you're asking questions to help people understand about how you're doing and what I need to succeed."

Q: *What happens if you don't advocate for yourself?*

A: "Then you're not getting the attention or help you need."

Q: *How do you feel about advocating for yourself?*

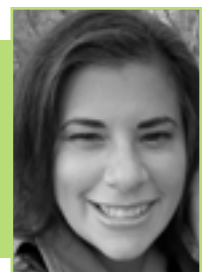


A: "Sometimes, I felt nervous and scared to say what I needed when I was a kid. But now it's not scary because they're just people and I usually know all the people in the room."

Q: *What's some advice you would give other teens about how to best advocate for themselves?*

A: "Think about it ahead of time. I write down notes to understand what's going on and so I don't forget what I want to say. Ask for help if you need it."

The current research and evaluation manager for the National Leadership Consortium on Developmental Disabilities, Cory Gilden is a former teacher, longtime autism advocate, and graduate of Partners in Policymaking, a program that teaches parents of children with developmental disabilities how to advocate for their children in school, how to talk to lawmakers, and how to push for appropriate health care needs.





I'm an autistic adult— and your advocacy can change lives

by Kerry Magro, EdD

Kerry Magro is an award-winning professional speaker, author, and autism self-advocate who wrote this article pro bono to support Autism DelawareSM. If you would like to have him speak with your company as part of a lunch-and-learn or other special event, visit [KerryMagro.com/](https://www.kerrymagro.com/) contact.

Autistic people just want a chance to succeed: I conveyed this message during one of my recent talks at JPMorgan Chase. I was part of a professional development session called Neurodiversity

in the Workplace for April's Autism Acceptance and Inclusion Month. In a world where individuals with disabilities, such as autism, are often overlooked in the workplace, it's crucial that we advocate for one of the most untapped talent pools that workplaces can consider.

I understand this firsthand from my journey growing up with autism. Struggling to find opportunities in a workplace, I found the resilience to focus on my key interests (such as theater) to hone my skills. I now share this message with you as a seasoned professional speaker who gets to speak with companies around the country both in person and virtually.

A huge part of advocacy begins with

initiating the conversation. Using your voice is vital for aiding those who may be voiceless or lack a platform to have their stories told. I do this work not only in the professional development presentations and workshops that I offer but also in my talks with schools across the country.

I also use my voice as the founder of a nonprofit by aiming to shape the lives of future generations of autistics. Recently, my advocacy helped a 26-year-old autistic adult secure a part-time job after he struggled to find any work. Through my years of advocating, I had found the network of connections to assist this individual. And he advocated in turn at one of my events by sharing his story of growing up with autism.

The need for advocacy continues in the Delaware area, where most self-advocates (including myself) have rarely received speaker offers. Companies need to realize that individuals with autism are more likely to stay at a job longer and take less time off from work. Plus, when considering the bottom line, the majority of reasonable accommodations cost very little.

Our advocacy can shape a future where workplace neurodiversity is not only accepted but celebrated, understood, and appreciated.

Advocate for employing autistic adults

“Adults diagnosed with autism spectrum disorder (ASD) continue to struggle with unemployment or underemployment issues at an extremely high rate, which has only been amplified during the pandemic. Studies estimate a staggering 50–75% of the 5.6 million autistic adults in the U.S. are unemployed or underemployed. Nearly 50% of 25-year-olds with autism have never held a paying job, despite having the skill sets and expertise to excel in the workplace” (<https://www.forbes.com/sites/jenniferpalumbo/2021/04/27/why-autism-speaks-is-encouraging-companies-to-hire-those-on-the-autistic-spectrum/?sh=4fd3980552a2>).

DAP's move to the DDOE

The Delaware Autism Program (DAP) moved in 2023. The state-funded program had been administered by the Christina School District and housed in the Brennen School in Newark. With a change made by the Delaware General Assembly, DAP is now part of the Delaware Department of Education (DDOE), housed in Dover, and called Autism Resources.

“As a statewide program,” noted DDOE Secretary of Education Mark Holodick, EdD, in a delaware.gov press release, “moving the office to a state agency just makes sense. The change allows us to better coordinate with other state supports and programs so, ultimately, we can better serve our children with autism.”

Here, meet the Autism Resources workgroup as they answer some questions concerning their yearlong effort on behalf of students with an educational classification of autism.



Pictured left to right are Autism Resources director Mary Whitfield, EdD, BCBA, and Autism Resources education specialist Nicole Zehnder, M.S., BCBA.

Why did DAP move to the DDOE?

“The Delaware General Assembly made the change through epilogue language, effective January 1, 2023. The move did not affect any Christina School District services, including the district’s Brennen School,” assures the workgroup’s director, Mary Whitfield, EdD, BCBA.

Prior to being named to this position, Whitfield taught and served as a school administrator, district instructional coach, and special-education coordinator in the Gwinnett County (GA) Public School system. With more than 18 years’ experience supporting students in public education, clinical settings, and higher education, Whitfield believes that working with local schools and the community can lead

Epilogue language is a Joint Finance Committee (JFC) revision to a budget bill under consideration in the Delaware General Assembly. During budget hearings, the JFC can insert language at the end of the bill that includes updates or guidelines on how the funds should be used and may include additional funding or a policy change.

to greater academic, behavioral, daily living, and vocational success for students with autism, allowing them to be productive, socially connected, and personally fulfilled members of society. To this end, Whitfield oversees the Autism Resources team.

The education specialist on Whitfield’s team is Nicole Zehnder, M.S., BCBA. When joining the workgroup, Nicole brought 10 years’ experience supporting people with disabilities, including children with autism at DAP. She has also served as a behavior analyst with the Christina School District’s REACH program and as a board-certified behavior analyst with the Red Clay Consolidated School District as well as the director of an in-home ABA (applied behavior analysis) program. Her goal with the Autism Resources workgroup is to foster relationships that help create greater support and success for the students and families within Delaware’s autism community.

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What are the benefits and challenges of this move to the DDOE?

“My team,” explains Whitfield, “which also currently includes one training specialist and an administrative assistant, collaborates closely with the department’s Exceptional Children’s Resources workgroup, which supports students with disabilities, including autism. We provide technical assistance and training to educators and families. As a statewide program, moving the office to a state agency allows us to better coordinate with other state supports and programs to better serve our children with autism.

“Information about the move,” continues the workgroup’s director, “has been shared since 2022 through press releases, media

coverage, newsletters, and school communication. Helping families and educators understand who we are and how we can help them remains the biggest challenge. [Our website](#) includes helpful information for those wanting to learn more.”

What are the highlights of the workgroup’s first year in operation? And what lies ahead?

“It has been a great year!” smiles Whitfield. “Through a state peer review committee, the Statewide Monitoring Review Board, and general inquiries, we have been able to provide more support this year than in years past and to more districts and schools, including charter schools. Support has been provided in the form of professional learning, behavior support, and general recommendations for educational program-

ming for students with autism.

“We have also offered several workshops to parents on various topics concerning their children with autism,” adds Whitfield, “and we are currently working to create a resource library for families to access specific tools to use in the home and community. Plus, we are continuing to build collaborative relationships with schools, families, and the community.”

Where can someone get more information about the Autism Resources workgroup?

Call (302) 735-4210, send an email to Autism.Resources@doe.k12.de.us, or visit the website at <https://education.delaware.gov/educators/academic-support/instructional-support/special-education/autism-resources/>.

Did you know...

Autism Delaware’s family support services are individualized to best meet a family’s needs?

Autism Delaware can provide comprehensive, accessible, family-centered support. Our dedicated family navigators and family support providers (FSPs) support families in assessing their needs and designing the next steps for their children diagnosed with autism or who have an educational classification of autism. And each family will have the opportunity to discuss how to put recommendations into action.

If you would like to receive Autism Delaware’s family support services, talk to your provider about a referral or contact Autism Delaware’s intake coordinator at (302) 224-6020, ext. 219.



New employees expand community outreach

Mia Wilson, PhD, joined the staff at the end of February as the new associate executive director (AED). Headquartered in the Newark office, Dr. Mia also frequents the Lewes office and the adult services program in Dover. In this capacity, she fosters relationships with the agency's many constituencies, directs communications and fundraising initiatives, provides executive leadership to all department activities, assists the executive director (ED), and will assume ED responsibilities when needed. Further responsibilities include directing the administrative side of developing and implementing services, programs, and budgets plus ensuring the compliance of audited financial statements and federal mandates.

With a master's and doctorate degree in psychology, Dr. Mia has accumulated nearly 20 years' experience in human services and social services on both the service delivery and business sides. Additionally, she holds a bachelor's degree in business marketing plus credentials as

a licensed clinical alcohol and drug counselor (LCADC) and a licensed clinical social worker (LCSW).

"On the personal front," says Dr. Mia, "I'm happily married to a wonderful military buff, and together we're navigating the joys and adventures of parenting. We have two adult children and one still in the midst of childhood antics. And recently, my nephew has become a cherished addition to our family, adding even more excitement to our lives.

"I come from a military family myself," adds Dr. Mia, "so I understand the values and challenges associated with it. At home, I have my hands full with a handful of energetic young men who keep me on my toes. We love spending time together, riding ATVs, and swimming. Although it's a rare luxury these days, I do cherish moments of relaxation whenever they come around—which isn't often with such a lively household!

"I should also mention that I'm quite competitive by nature, always up for a challenge or a friendly game."



Dr. Mia can be reached by email at mia.wilson@autism-delaware.org or by calling (302) 224-6020, ext. 208.



Anisa Monforte joined the fund development and community engagement staff this past August as the new development coordinator. In this position, Anisa serves as the primary point of contact for all gift and data processing. Not only does she track, report, reconcile, and acknowledge donations made to Autism Delaware, but she also maintains the database. Further responsibilities include assisting with developing, maintaining, and reporting on the department's budgets; planning and assisting with events; and working with stakeholders to support the agency's mission as well as the department's goals.

With a degree in education and a background in health care, Anisa holds two beliefs: that advocacy in education is crucial and that Autism Delaware represents impactful change, innovation, and acceptance. Working from these beliefs, she looks forward to creating new bonds and strengthening the old bonds with the autism community.

"Just as I've been active in my local community," explains Anisa, "I'm excited to be a part of a movement that positively impacts the autism community."

Anisa can be reached by email at anisa.monforte@autismdelaware.org or at (302) 224-6020, ext. 203.

Meet our new FSPs

Our family support providers (or FSPs, for short) are the centerpiece of the Autism Delaware Autism Care TeamSM (ACTSM) program. Not only are they highly trained and credentialed professionals, but they are also the parents of children on the spectrum and have firsthand knowledge of the challenges that families face. As a result, they bring essential skills and experience to every meeting and can help a family create an individualized program of services that best meets the family's needs.

Here, meet Paula Broody and Imani Oliver.

How can an FSP help me, my child, and my family?

[Click here for the answer!](#)

Paula is a new bilingual FSP who supports both English- and Spanish-speaking families across the state.

Believing that all families need to feel heard, Paula brings to parent meetings more than 10 years' experience as a translator, advocate, and family representative and intermediary in a range of complex situations, including the public school system. She also has experience providing valuable information and resources, collecting data and conducting workshops, identifying barriers to services, and supporting the community through education.

Before joining Autism Delaware as an FSP, Paula volunteered her time to provide resources and information to improve access to care while also translating communications material. And as a bilingual parent consultant at PIC of Delaware, Inc., she provided assistance to more than 450 families through direct advocacy efforts and support of the parents and youth with disabilities. She also coordinated and facilitated discussions and workshops focused on special education and health care, assisted in the development of training and information materials (videos, social media, and other outreach initiatives), and conducted workshops in Spanish on topics related to special education and effective advocacy.



As a new FSP headquartered in Kent and Sussex Counties, Imani wants to assure southern Delaware families affected by autism that need help: "It's always about what's best for your family.

"As we all know," continues Imani, "the effect of autism on a family is very broad. Addressing it all can overwhelm parents, especially

those with children who are newly diagnosed.

"As a new FSP," adds Imani, "I bring a background in leadership in both health care and teaching. Through my work in these two diverse fields, I've personally experienced more than my fair share of obstacles. And this experience combines with my life and goals as the parent of a child on the spectrum to create a unique understanding of the needs a family faces as well as the path to addressing those needs.

"This is why I'm here at Autism Delaware: to help families with children or loved ones on the spectrum, support them on their journeys, and be their personal resource guide—one family at a time."

Looking for a job that supports the autism community?

Click here:

<https://www.autismdelaware.org/about-us/work-with-us/>

The first 60 years of autism advocacy **Continued from p. 3**

view autism as a disability. From this theoretical underpinning, the neurodiversity movement makes several demands, including the recognition and acceptance of the value of cognitive variation as a form of biodiversity and hence its positive contribution to groups, communities and societies (the social-ecological perspective) and equal rights leading to an end to discriminatory policies and practices.”¹⁴

To this end, the Autistic Self Advocacy Network (ASAN) has “an ongoing campaign to shift April from discourse about autism awareness toward discourse about autism acceptance, centering Autistic voices and creating a more inclusive, accepting world.”¹⁵

“The recognition of Autism Acceptance Month in April is a powerful message that we belong in society,” agrees self-advocate James Turner III. A 2022 graduate from the University of Missouri, St. Louis, Turner holds a bachelor’s degree in political science and government and currently works as a legislative aide in the Missouri General Assembly.

“The more we promote acceptance,” continues Turner, “the more autistic people will be able to embrace who they are and let the world recognize that we are capable and amazing human beings.”

“Autism Acceptance and Inclusion Month gives those who experience chronic, social anxiety a voice where they were struck silent in years past,” adds author and educator Clifford Brooks. “It not only informs those with friends and family on the spectrum, but it may also create an aha moment for anyone unaware they’re autistic. This is a precious revelation, that their feeling of otherness isn’t a curse or something to be ashamed of. Like me, they discover the reason for their intense unease and now have a place to start building a new life.”

Brooks’s ultimate goal is to provide relief through a gentle delivery of accurate information. To this end, the Georgia native created *Adulting with Autism* on the Teachable platform and is kicking off his Autistic Writers’ Workshop with the UCLA Extension.

“I have seen the difference between an environment where acceptance and inclusion were practiced and where they were not,” acknowledges self- and parent-advocate Heather Petit. The New Castle County mother of four is the director of strategic IT operations in a global contract research organization. She is also preparing for chaplaincy training this spring. Her social justice ministry has for several years focused

on disability rights and neurodivergent self-advocacy.

“Even if we are only collectively practicing one month of the year,” continues Petit, “it gives people the opportunity to start recognizing what ‘good’ looks like, what it feels like to have multiple people casually accommodate you because, of course, you are welcome here. Not just if you’re easy to be around, no bother, but also if I have to do something to make it possible for you to stay—or to show up in the first place. It can take practice, sure. And months like April are where we start. Even better, the year later, as we watch the people we made room for take charge now and make room for someone else.”

In sum, one man’s need for awareness 60 years ago morphed with each new generation. But as past generations of autism advocates have learned, making room for everyone at the proverbial table requires a lot of information, hard work, and support. With the current autism prevalence rate at one in 36,¹⁶ even more will be required of autism advocates. Thanks to Bernard Rimland—and the countless number of autism advocates who worked tirelessly over the past six decades—we continue to have an opportunity to add our voices to the conversation in April.



After three years’ work by Autism DelawareSM autism advocates, the Alex Eldreth Autism Education Act was signed into law on August 29, 2018, by Del. Gov. John Carney. The new law funded the training and coaching of teachers who educate students with an educational classification of autism.